

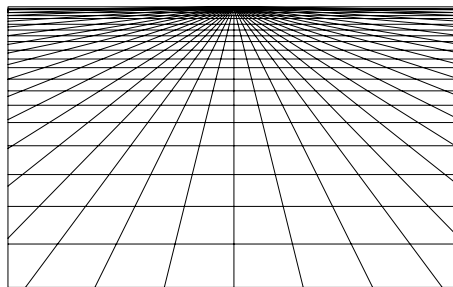


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A Scenario Assessment on Privacy Dilemmas Rising from the Application of Information and Communication Technology (ICT) in the Form of a Tracking and Tracing Network for Sustaining Long-Term Home-Care for Dutch Mentally and/or Physically Disabled Individuals and Elderly: The **EL**derly and **DIS**abled Personal Security and Assistance System (**ELDIS**)
Commission for Health Care in the Netherlands

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2000/2001

Total Word Count: 23425

Abstract

This thesis is the result of an assignment commissioned by the Institute for Rehabilitation Research (IRV) in the Netherlands. The objective here has been to assess -by means of scenarios- potential privacy dilemmas rising with the implementation of a tracking and tracing network for elderly and disabled individuals in the country, to accordingly present a series of recommendations to the institute. The recommendations expected were to present possibilities for changes and/or adaptations on the technology conforming the network. However, the scenarios developed, clearly demonstrated that privacy dilemmas rising from the application of this type of information and communication technology are not solely based on the technological device conforming such a network. As authors like Bijker, Tidd and Ripp, among other in the STS field have stressed, the social sphere in which technological development occurs influence and form its development as well. In this case, special consideration needed to be given to the array of actors involved, their capabilities, interpretations and interests. In base of the findings, the recommendations broadened to include long-term and short-term changes/adaptations on both the technical device and the social sphere of the network. The recommendations vary between technical adaptations, re-considerations aimed for the country's health care system, and reforms on various established policies, to the need for changes on policy-makers attitudes. Only when these recommendations are put into action will the network's patient information be a step further to be sustained.

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Part One

Introduction and General Issues

Living in an era where rapid development and dissemination of Information and Communication Technologies (ICTs) promote easy access to different kinds of information, we find ourselves at times entangled amid the right for access to -and use of information, and the boundaries of what constitute an individual's right to privacy. This trend towards developing faster and more accurate ICTs increasingly endangers each citizen's right to privacy, causing decisions made and actions taken in their regard, to increasingly involve ethical and legal dimensions. These decision-making and action taking processes create themselves at times dilemmas in regards to the design and functions such technologies should include. The dilemmas created in face of this type of technological development seem to increase when the decisions and actions involve individuals with physical and/or mental disabilities. Individuals, who often can not supply their own needs and/or stand for their own views and rights in today's ever-changing society. Because of their special needs and limitations it is necessary for them to be constantly assisted and/or represented by third parties in their daily routines and interests, situation that has caused increased awareness in Europe's policy-making processes. An increased awareness towards these individuals needs and rights, especially concerning the growing elderly population¹ seems to be emerging in the EC.

An advanced member-state of the Union in planning and implementing reforms within health care services in general and, particularly for the elderly and mentally disabled is the Netherlands,

¹ Based on Romano Prodi's (President of the European Commission) speech in November 1999 in Florence, where he describes the crisis the EU faces:

which has a relatively well developed system of long-term care². The country's Ministry of Welfare, Health and Cultural Affairs, and particularly the Department on Policies for the Aging are intensely focusing on: 1) expanding service capacity in home- and day care, 2) reducing use of institutional care, and 3) reducing the costs of long-term care in the country³. According to the above governmental agencies, these objectives can be achieved by strengthening volunteer help and professional services in communities, by improving adjusted and sheltered housing arrangements; and, by enhancing social participation of these individuals in society as a whole⁴.

Recent policy-oriented studies suggest that care for the elderly in the Netherlands is developing into a more differentiated system with multiple ways of dealing with chronic health problems and disability in later life⁵. As a result, a great amount of attention is now given on strategic innovations in community care, where it is believed that viable alternatives to present long-term institutional care⁶ can be provided. Hence, research on a variety of possible solutions, among them technological -such as Information & Communication Technologies-, has increased in recent years.

A leader among institutions doing research in rehabilitation technologies using ICT's is the Institute for Rehabilitation Research (IRV)⁷ in the Netherlands. The institute is a center for rehabilitation studies specialized on applied scientific research, and collection & dissemination of

"...By 2030, 25% of the population in the five largest EU countries, the UK, France, Germany, Italy and Spain, will be over 65, according to the calculations of Professor Tito Boeri, director of the Rodolfo de Bendetti foundation in Milan. In 1950 that figure was just 9%". (as cited on ELDIS full-project proposal; 31.03.2000, p. 7)

² Coolen, J.A.I.; 1993, p. Vii.

³ Coolen, J.A.I.; 1993, Preface & pp. 1-2

⁴ Coolen, J.A.I.; 1993, p. 2

⁵ Coolen, J.A.I.; 1993, p. 1

⁶ Coolen, J.A.I.; 1993, p. 1

information and knowledge. The institute's objective is to improve intervention programs, facilities and equipment for persons with long-term disabilities and handicaps⁸. Research here is mainly focused on aid and rehabilitation technologies for elderly and mentally and/or physically disabled individuals in order to assist their needs and restore autonomy and independence to their lives. The IRV believes in researching and developing aiding technologies as a means to solve, not only Dutch, but also Europe's rising need for care services and their costs. Among some technologies researched on are various personal alarms to be used by handicapped individuals in general but especially focused on use for the elderly. Through its experience, the institute has become increasingly aware that personal alarm infrastructures have been based on fixed telephone lines serving individual alarm units, and that the change of trends towards more mobile communications enables the development of an alarm system not restricted by physical boundaries like the home. It also believes that the development of such mobile information and communication technology will allow its users to experience higher mobility. Mobility, that could improve handicapped individuals' quality of life by restoring a sense of independence and autonomy, as well as alleviate the people who care for and/or assist them and reduce care costs.

Because the institute wishes to become a promoting partner for this type of mobile ICT for use in the Netherlands, it has in collaboration with public and private organizations from France⁹ and Israel¹⁰ elaborated a research project for the development of an “**EL**derly and **DIS**abled Personal Security and Assistance System” (ELDIS). With the development of ELDIS they intend to

⁷ This section is based on IRV's web-site, and information contained in the ELDIS full project proposal. For more details on the IRV see: <http://www.Irv.nl>, or <http://www.revalidatiehandicap.nl>.

⁸ As noted on www.irv.nl

⁹ The French collaborators are: THOMSON-CSF, which is the system designer and co-ordinator of the whole ELDIS project and CEA-LETI, which is conducting research in algorithms for positioning. For further information on these two partners see: www.syseca.thomson-csf.com and www-leti.cea.fr

coordinate a technological network for alleviating the demands -among others- of the growing elderly population. The network will mainly consist of a tracking and tracing device connected to a (technical/social) system¹¹ to supply assistance to elderly and mentally/physically disabled individuals with high risk of falling and/or increased wondering behavior. Besides its main functionality of monitoring and tracking objects, and professional & individual users in health care applications, its design and functions are expected to register, measure and collect the medical parameters of the individuals in order to facilitate assistance.

The ELDIS consortium aims to promote and legalize a personal security and assistance system for mentally and physically disabled individuals based on their most common needs and capabilities. They believe that participation in the ELDIS project will allow the Dutch partners to actively collaborate in and influence necessary decision-making processes to facilitate the development of an innovation system with some of the following technical features¹²:

- Sensing, measurement, recording and analysis of medical parameters (i.e. blood pressure, heart rate, etc.)
- Emergency Panic button
- Central and local positioning capabilities
- Two-way messaging network

The anticipated design, features and tasks this technological system is expected to include can raise discussions around privacy sustenance. Like technological innovations in general, the development of this tracking and tracing technological system called ELDIS resolves in theory many practical problems but creates in praxis a great deal of dilemmas and debates. The

¹⁰ The Israeli partner is COMMTRACK. They serve as system and components designer. For more information see www.matimop.org.il/newrdinf/company/c2250htm.

¹¹ “System” is used here as the intricately connected coordination of things and people to form part of ELDIS. Here, no distinction between what pertains to things and what to people is made due to the intrinsic interactivity of the connection. The terms “system” and “network” are used interchangeably in this thesis.

¹² ELDIS Full Project Proposal; 2000, p. 4

dilemmas confronted with upon development of a network like ELDIS and to be assessed in this thesis as requested by the IRV are:

How to develop and implement a technological network that systematically fulfills the constant need for caring, monitoring and assistance of these individuals, while sustaining their right to privacy as dictated by Dutch privacy-regulation acts (WbP/WGBO) without conflicting with them? Which design and/or function of the technological device is more prone to create dilemmas related to privacy sustenance as dictated by the Netherlands? And, how can the IRV as part of the ELDIS consortium and commissioner of this thesis design and develop a system in accordance with Dutch privacy regulations?

Solving such dilemmas becomes crucial in early research phases before deciding the design and functions such a system will include. In this regard, special consideration needs to be taken not only around privacy regulation and the technological device, but around the system's users, their needs and capabilities, and, what is culturally given and hence ethically/legally accepted in the specific society. As the questions presented by the IRV for this thesis show, when developing specialized technology like the one intended for ELDIS, technological developers often tend to take actors in such networks for granted. They often focus on developmental phases (where the interactions occurring are less clear and obvious), mainly on choosing the best performing design and function the technology shall include and distance themselves from implementation one.

Technological developers often seem to understand technological development, -in this case a mobile personal alarm enhanced with tracking and tracing capabilities among others- as autonomous instruments to be used by just anyone, at anytime, in any circumstance and place. It is however, in implementation phases where difficulties and dilemmas usually increase.

Contrasting technological developers' views are policy-makers and -relevant for this case-

regulatory agencies with control responsibilities. They often pose as critics representing, protecting and serving society, resisting at times to support research on or development of new technologies, which at first hand seem risky and hazardous for society. They act as limiting forces for the development of technologies that could bring some benefit to the same society they are out to protect. This polarity is the result of a two-track approach society has relied on until recently separating promotional activities from control and regulation ones. Institutions have been set to separate regulatory agencies from technology-promotional ones acting often as countervailing powers¹³. Such approach is ineffective in solving dilemmas rising with the development of new technologies because instead of providing early warning and perspectives on the impacts of technologies, it serves as a mere after-the-fact gatekeeper¹⁴. This manner of approaching society becomes embedded in deterministic views like Technological Determinism and Social Determinism. By adopting such deterministic views, developers on one side, run the risk of having invested resources, time and efforts in vain because the technology developed becomes futile for its intended proposes while policy makers on the other, run the risk of halting the technological progression demanded by the same society they represent, acting sometimes as a brake on implementation of potentially profitable technologies¹⁵ for that same society. An early, in-research stage assessment though, could increase the technology's likelihood for acceptance and correct use, in addition to the society's resulting benefits with the correct use. Such type of assessment and of understanding the world is made possible by the field of research concerning interactions occurring and relationships built between society, science and technology, namely: Science and Technology Studies (STS). The field opens for an in-depth constructive assessment

¹³ Rip, A.; Misa, T. & Schot J.; 1995, p. 2

¹⁴ Rip, A.; Misa, T. & Schot J.;1995, p.2

¹⁵ That is not always the case. Technological development is not always necessary positive to a specific society, even though the society could believe it is.

surrounding the development of the ELDIS tracking and tracing network in the Netherlands in base of the country's stipulated privacy regulatory acts. What has been called "the social shaping of technology" by various authors on the field¹⁶ will be utilized as base for the building of scenarios and constructive assessment to follow. STS explains the relationship between science and technology as a feedback loop interconnected as a seamless web where technology does not develop according to an inner technical logic but is instead a social product, patterned by the conditions of its creation and use¹⁷. Where every stage in the generation and implementation of new technologies involves a set of choices between different technical options and, where alongside narrowly "technical" considerations, a range of "social" factors affect which options are selected - thus influencing the content of technologies, and their social implications¹⁸. This thesis hence seeks to constructively assess the questions asked and recommendations to be given lying on the assumptions held by the STS field. Assumptions, which distance themselves from technological- and social deterministic views in various arenas and in the way they see, understand and treat society, science and technology, specially rejecting the manner these deterministic views preconceive the way society, science and technology influence each other. STS rejects technological determinism on their views in regards -among others but chosen for its relevance for this thesis- to technological development where technology, sensed as an autonomous agent driving change, is accepted as having a determining and prominent place in society. For them technology, like the weather, is autonomous. Followers of this view see technological change as a cause and everything that follows as the effect or impact¹⁹. For them,

¹⁶ Among them are Mackenzie and Wajcman in their book with the same title "The Social Shaping of Technology"; Open University Press 1985

¹⁷ Robin Williams and David Edge; *Research Policy* Vol. 25, 1996 p. 1

¹⁸ Robin Williams and David Edge; *Research Policy* Vol. 25, 1996 p. 1

¹⁹ Based on: Winner; University of Chicago Press 1986, p. 10

invention once introduced into society takes on a life of its own²⁰. Opposite of this view is –the also rejected by STS- social determinism. Contrary to technological determinism they argue that society is the autonomous force that drives and shapes technology, implying that society is the driving agent of development and change. Alike technological determinism they understand the results as a natural cause and effect situation.

With the above arguments in mind, it is this investigation's main intention to build a platform - consisting of scenarios- for the IRV. This, in order to present an assessment of the design and function proposed for the ELDIS network, in regards to sustaining privacy. As mentioned earlier, the base of the assessment is STS view on Technological Development. Possible Dutch privacy-regulation issues that could appear with a specific design and/or function(s) of the technology comprising the ELDIS network and which could affect the system's capabilities, development, implementation and use will be analyzed and discussed. After this is done, concluding comments and recommendations will be presented to the commissioner of this thesis. The IRV in the Netherlands commissioned this thesis with the intention of foreseeing and hence sustaining the target individuals' right to privacy on implementation and use of this Tracking and Tracing Technology (TTT). They believe that by adapting specific technical features for ELDIS, successful implementation and use of the network in regards to privacy sustenance will be guaranteed. They understand though that dealing in an early research phase with potential, emerging privacy issues (based on the users) can help anticipate setbacks on further, more practical phases such as implementation. The manner, in which they work and organize their activities, seems to resemble some STS views. It seems however, that they merely use it in

²⁰ Based on: Smith and Marx; MIT press 1996, pp.ix-xi (introduction)

relation to the managing of their own activities, taking it for granted within their applied research strategies. They seem only to some degree²¹, aware of the vital need to include other factors - besides design and function based on its users needs and capabilities in order to sustain privacy in this case- for effectively developing, implementing and using such a technological system.

Consequently, this investigation intends to shed light on Dutch general and health-care regulations to enhance and analyze queries rising in regards to the sustenance of the right for privacy of target individuals in the ELDIS network in face of this type of technological development. In order to reflect upon the privacy-boundaries rising within the user-technology relation, as well as to analyze its possible consequences for the system as a whole; it is crucial to understand privacy as defined and used in the (Dutch) Personal Data Protection Act (2000)²² and the (Dutch) Medical Contract Bill (1995)²³. Privacy hence, is for the most part of this investigation, treated as an object of analysis to achieve the purposed goal, namely:

- Based on the capabilities and needs of the elderly and disabled, what privacy dilemmas could rise with a specific design and function of the ELDIS network? And, according to the findings submit a series of recommendations for the IRV on potential adaptations and changes on the technology to help avoid these dilemmas from rising.

In order to accomplish the above mentioned task, two sub-questions will be addressed and examined in the form of scenarios:

1. Which Dutch privacy regulation(s) rise(s) within a specific design, function and/or among a specific user of the ELDIS system and what can the implications for the system be?

²¹ It seems that the IRV is taking for granted other situations and attitudes besides privacy regulation that could also affect the use of this technological system. Further development of this comment will be presented in parts III & IV.

²² Based on unofficial translation found on: <http://home.planet.nl/~privacy1/wbp.htm>

²³ Based on Dutch version found on: <http://www.healthlaw.nl/wgbo2.html>. No English translation exists for this Bill.

2. How is “privacy” conceived and used in the (Dutch) Personal Data Protection Act, the WbP (Wet bescherming persoonsgegevens, 2000 and the (Dutch) Medical Contract Bill, the WGBO (Wet geneeskundige behandelingsovereenkomst, 1995)?

As stressed earlier, the main concerns of these questions revolve upon the conceptualization of the term “privacy” by Dutch policy-makers and the practical sustenance of an individual’s privacy -applied to the target groups- as the means to achieve a development, implementation and function of the ELDIS network in accordance with the country’s privacy-regulation boards. After this task is done a series of comments and recommendations specific for ELDIS will be presented to the IRV in the Netherlands, as well as general STS conclusions.

Following is the outline of this investigation, where the issues addressed, and methods used are established in a more detailed manner. The thesis is divided into four parts. This first, introductory part presents the general objectives and arguments this investigation is built upon, as well as its commissioner the Institute for Rehabilitation Research (IRV) in the Netherlands and its objectives with the research for an elderly and disabled personal security and assistance system (ELDIS). The section concludes with a specific presentation of the objectives and intended functions of this thesis for the ELDIS project, alternatively connecting them to STS. On the Part Two, a detailed description of the technical properties, anticipated functions, and use the technology at hand is expected to achieve is provided. The contemplated network users it shall involve will also be specified here. Part three of this thesis, seeks to rummage among the prevailing conceptualization, definition on- and use of privacy by the Dutch privacy-regulatory boards. After doing so, a series of possible scenarios will be created based on relevant literature and interviews with key individuals from the Dutch Alzheimer Foundation. These scenarios constitute Part Three. They are envisioned to demonstrate the various relations appearing within

such a network, in order to accentuate and discuss how decisions made -when grounded wholly on either specific social or technical attributes- will, in given circumstances influence the outcome and hence possibilities of creation and implementation of such type of networks. Once more, in an STS perspective, the scenarios intend to unveil the vital interactions occurring, and relations built during the planning; development; application and use phases of such ICT network, to show that when disregarded the network's proclaimed functionality may be threaten. They are to shed light on, and problematize the relations created in face of technological development in order to show how conceptualizations of theoretical notions -like privacy in this case-, influence these relationships and hence the development of such innovations, and how developers and parties involved, best can deal with them. These scenarios form the core of this appraisal. In order to accomplish this assessment in a fulfilling manner, it is crucial to first determine and clarify necessary factors -like technical features of the technology, its functionality and use of the network- as well as to categorize the potential target users that construct the ELDIS network. As mentioned above, the objective here is to contest -by using STS- the values and roles of each factor constituting the ELDIS network. Based on STS literature this thesis intends to illustrate once more society's need to detach itself from deterministic views, which can grant incomplete pictures of society's interactions, affecting at times the intended uses, functionality and hence acceptance of such innovations. Part Three concludes by returning to the locus question of this investigation:

- How can the IRV, -based on the essential needs of the network -, both anticipate and influence developing privacy-regulation standards to promote the development of a Tracking and Tracing Technological System, which sustains an individuals right for privacy as dictated by the Dutch authorities?

Centered on the issues raised and debated on throughout the other chapters the concluding Part Four presents a series of -STS perspective- comments, conclusions and recommendations around considerations for developing technological innovations in ICT to be used by vulnerable individuals like the elderly.

Part Two

Milestones for the development of ELDIS in the Netherlands: Bridging the gaps

Introduction

Policies are being developed in the Netherlands not only to enable mentally and physically disabled individuals to maintain as independent lifestyles, autonomy and, quality of life as possible but also to control the country's continuous rising health-care costs attached to increased growth of the elderly population. Among various policies developed for this objective is, the so-called Substitution Policy adopted to partially replace institutional care for home- and community cares²⁴. With the adoption of this policy, varying types of health-care provisions such as short-term stay in institutions, day-care facilities and intensified home care²⁵ have emerged.

The main long-term objective with the adoption of this and related policies, is to enhance social participation of consumers of health-care provisions by leading independent lifestyles within their own homes as long as possible. Various projects on sheltered housing are being developed to support and obtain these objectives. The latest ones perceive care as a layered system based on three components providing incentives for informal support. These are²⁶:

- independent housing which can, if necessary, be sustained by the regular community services,
- sheltered housing with additional support from a care-provider or service-center,
- residence in a home for the elderly/disabled or in a nursing home

It is with the above aims and incentives in mind -among other- the ELDIS network has been

²⁴ Coolen, J.A.I.; 1993, p.6

²⁵ Coolen, J.A.I.; 1993, p.5

²⁶ Coolen, J.A.I.; 1993, p.5

proposed. The objective with the development of a tracking and tracing network like ELDIS is to meet and fulfill security & medical assistance and independent living requirements for its primary users. The network is expected to work as a cost-effective personal security system providing medical assistance, acknowledged emergency panic button, perimeter monitoring, positioning information and (fixed/portable) searching units and two-way messaging for the elderly and disabled within their community, surrounding areas, or in any specific region they find themselves in. However, like technological innovations in general, this proclaimed “technological network” can not function on its anticipated technological features and good intentions alone. Reality, that seems forgotten or taken for granted by developers during research and developmental phases. The importance of factors like users, factual functionality and need for maintenance of such networks is usually first acknowledged on later but crucial as well implementational phases.

As stated in the introductory part of this thesis, when taken for granted, these factors can affect the intended purposes and uses of this type of innovation. It is therefore, crucial, to already in early research phases consciously anticipate and scrutinize the platform such networks as a whole will be built on and include. In basis of this, the following sections in this chapter intend to chart, assess and discuss the network’s user and actor platform, it’s technical features and functionality, and other possible sources intended to form the ELDIS network. In addition to chart the above - and more obvious- relations in the network, other less obvious -or at times even considered “indirect”- relations such as health care and privacy legislation policies in the Netherlands will be presented and assessed to demonstrate their influence on the technological development of a system like ELDIS.

Shaping a Network: Constituents and Representations Forming ELDIS

As is well known by now, technology²⁷ is not an autonomous phenomenon existing in itself, exogenous from society. It is instead the sum of applications, knowledge, practices and skills available in a society. Technological development, -in this case of a technological network for tracking and tracing elderly and disabled individuals- is thus not merely technically²⁸ related to artifacts. It also includes complex and multilateral real-world interrelated factors and representations including economical, organizational, political, communal and socio-cultural²⁹ aspects³⁰. The way innovations like this one occur can not be standardized to a one sided sphere, like technological design. Instead, the success or failure of innovations frequently depends on their ability to cope with the dissimilar constituents integrating the system³¹. In this regard, the ELDIS network does not behave differently from other technological systems. By mapping the needs and capabilities of its potential users and assessing the likely design and functions the system shall include in relation to them -based on the country's privacy regulatory boards-, the social construction of the system shapes already now an area of its own further development. With this in mind, it is the purpose of this section to introduce and discuss possible variants and constituents and their reciprocal relations conforming the ELDIS network. These variants or constituents roughly include the technological design (hardware/software), the social groups (health care-receivers and providers), externalities (external actors, reception), and the functions & structure of the system, among others. It is important to stress though that these variants are not

²⁷ As defined in The Collins English on-line Dictionary; 1998, HarperCollins Publishers:

1. the application of practical sciences to industry or commerce. 2. the methods, theory, and practices governing such application. 3. the total knowledge and skills available to any human society for industry, art, science, etc.

²⁸ As defined in The Collins English on-line Dictionary; 1998, HarperCollins Publishers:

1. of, relating to, or specializing in industrial, practical, or mechanical arts and applied sciences. 2. skilled in practical and mechanical arts rather than theoretical or abstract thinking. 3. relating to or characteristic of a particular field of activity.

²⁹ Socio-cultural aspects as understood in Managing Technology in Society; 1995; p. 29: the patterns of social relations, systems of interpretation, and beliefs among others.

static; they shape and reconstitute each other's identities and functions within the system and consequently, change³².

The ELDIS Network: Users and Actors Involved

As stated elsewhere, technological systems are not autonomous but the sum of the interactions and relations of its components, and hence, subject to factors like space, communities and meanings. In the case of the ELDIS network, these factors are interpreted in basis of the system's intended users; i.e. applications for Dutch health care and more explicitly, physically and/or mentally disabled individuals and the elderly. It is here that IRV's main task revolves. Because the complimenting set of technologies in the network open for application areas other than health care, the institute has investigated and specified feasible user groups for ELDIS. They have identified various groups of individuals with fall risk, heart conditions, wandering behavior, memory loss and/or mental retardation as potential prime users of the network. Although IRV's focus on product development lies on health care applications where ELDIS will primordially be used by care-providers and care-receivers, it has also identified potential application areas for the future (see figure 1.)³³.

³⁰ Mackenzie, D. & Wajcman, J.; 1999, pp. 10-11

³¹ Rip, A.; Misa, T. J. & Schot, J.; 1995, p. 167

³² The Social Shaping of Technology; 1999, p. 114

³³ ELDIS: Dutch Work-plan; 2000, pp. 9-10. Reprinted with permission granted by the IRV.

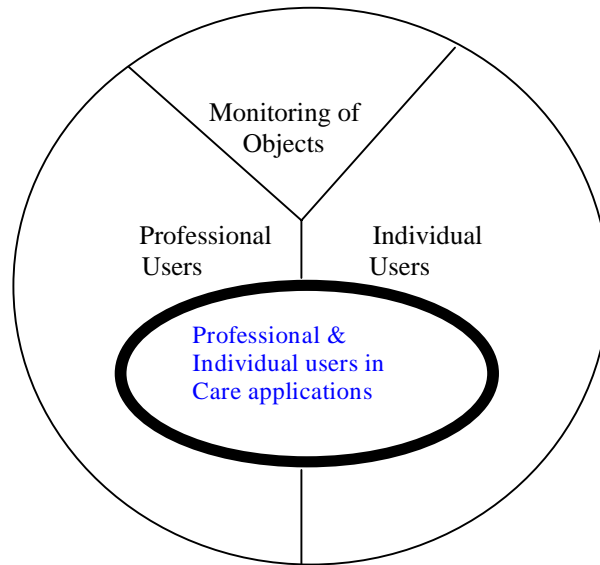


Figure 1: All possible application areas for ELDIS as identified by the IRV. Albeit various application possibilities, the prime application for the development of this technological system lies on health care.

Figure 1 demonstrates the variety of potential applications for a network like ELDIS. These applications can be extended to non-health care users to include tracking and tracing of non-human targets like artifacts and animals. Tracking and tracing of artifacts and animals however do not open directly –at least yet- for discussions around privacy sustenance like human targets do³⁴. It is first with the development of a system like ELDIS, with the capability of tracking, tracing and measuring the health parameters of human targets that discussions around sustenance of privacy according to legislation arise. As shown on the figure, ELDIS’s main application areas include monitoring and tracking health care professional and individual users. Amongst the system’s target application, that is, the Dutch health care system, the following groups have been identified as prime applications for integration in the system:

³⁴ Even though tracking and tracing of non-human targets and “healthy”³⁴ individuals also represent potential applications within the network, they will not be considered here due to their irrelevance for this investigation. On

- Mobile health-care workers (i.e. professional workers, volunteers, family members caring for theirs).
- Mobile elderly and temporary/permanently disabled individuals with a need for emergency calls and assistance.
- Persons with certain temporary or permanent conditions, such as fall or blackout risk, heart conditions, wandering behavior, memory loss and/or mental retardation.

These users can be categorized among them as well, into primary and secondary users. This categorization could become crucial for delivering not only the expected services intended for a specific group, but for supporting the system's functionality and integration, in addition to maintaining the target user's privacy. Care-receivers, that is, elderly and/or disabled individuals or any third party directly representing them, fall under the primary user's category. These are individuals with need for assistance and/or partial or complete care supervision for themselves or theirs. Care-providers, alternatively become secondary users. These are mainly health-care professionals such as nurses, doctors, patient organizations, etc. and/or volunteers working to supply care-receivers with the necessary supervision and care.

The functions and support expected of the ELDIS network can vary respectively according to the target user's needs and capabilities. For example, health care-providers for elderly and/or disabled individuals tend to be mobile, having to visit patients around the community they serve. In order to fulfill these care-duties in a satisfying manner they must resort to the use of mobile phones, portable computers and/or personal digital assistance organizers. Because of Dutch Social Security regulations, care-providers are required to accurately register the services they provide³⁵, forcing them to constantly introduce new and more effective technical solutions allowing rapid and accurate registration of data. Data entry hence, becomes the core of their

the other hand, "healthy" human applications will be referred to merely as a subject of comparison when necessary to emphasize the changing needs and capabilities of applications within health-care.

service-supplying activities, thus freeing them from tedious and long paperwork hours, granting them hence more time to spend with the people they care for. It is the collection and registration of medical information of individuals in electronic databases, which have become the focus of legislative forces in the last decade or so. It is therefore, that laws like the Personal Data Protection Act and the Medical Contract Bill in the Netherlands have been put to effect; to protect individual's personal data from illegal or incorrect registration and use. But, when mobile technology made available by ICTs is enhanced with constant monitoring and recording of the medical parameters of chosen individuals, as well as their tracking and localization, the boundaries charted through legislation become once more entangled and unclear³⁶. Subsequently, the constant need to review and amend discussions and legislation in regards to -at times antagonizing issues like- providing accurate and effective health care services, society's right as a whole to access and use information, and, a single individual's constitutional right for privacy in this case, increases. Conversely, we find those individuals in need of special care, namely the elderly and/or mentally/physically disabled. Many of these individuals are still quite mobile and expect services to be provided within their location in case of an emergency such as falling. Reality however, differs from these individuals' expectations. Often, they do not receive the necessary help because they are alone when emergencies occur. In case of fall for example, they often can not reach or operate the alarm button or intended communication's device, having to wait for someone to find them and assist them, which can discourage them to be mobile and carry independent life styles. Many of these individuals like elderly suffer from cardio-vascular conditions putting them in need of constant medical monitoring. Solutions proposed by Networks such as ELDIS could in theory solve this mobility problem but create in practice regulation

³⁵ Changing Care for the Elderly in The Netherlands; 1993, p. 25-26

³⁶ A detailed discussion on this issue will be presented on Part III of this thesis in the scenarios.

controversies in regards to the needs of monitoring and privacy³⁷. As can be seen from the above two examples, with the proposal of technological solutions like ELDIS, conflicting interests among the different actors' needs alone are already at stake from early research phases. These conflicts of interests tend to increase when other factors and actors like policy makers' agendas, technological developers' intentions, and investors' economic interests are also taken into consideration besides users needs and capabilities. These actors will form as much an integrated part of ELDIS as the users.

Besides policy-makers, engineers and investors, there exist other types of actor representations within ELDIS. These actors include researchers, system managers and marketing & promotional agencies among others. These actors' influence and authority are often regarded as exogenous from the system, especially within design and development phases of new technologies. Contrary to the established belief and practice though, these users form an integral –if not constant or obvious- part of any system to be developed. Together with the system's other actors among which are the users, they will socially shape the intended technology. In this sense, a fulfilling and continuous assessment of the polarized user interpretations, interests, needs and standpoint within a technological system like ELDIS is necessary. By treating some actor representations as external from the system in stages like research, production and even marketing, conflict of interests as well as unforeseen dilemmas related to them can appear. As a result, this will hinder further development in implementation, stabilization and closure phases as well as the system's intended functionality.

On the prior section, the possible user and actor representations to from part of the ELDIS

³⁷ A detailed discussion on this issue will be presented on Part III of this thesis in the scenarios.

network have been discussed. Users needs and intentions alone though do not grant a technological system like ELDIS the necessary components for it to function. Other constituents like the system's expected technical features, design and functions conform as essential and integrated part as the users and actors expected to form ELDIS. These are necessary not in relation to themselves but in relation to the interpretations and use given to them by human factors, which will itself influence them (human factor) in their daily lives and routines. The next section offers then a description of the technical properties and functions expected to compose the ELDIS system.

The ELDIS Network: Its Technological Features and Functions

The artifact's design, technical features and functions also form part of the constitution of such networks because their relation to the users created through interpretation and use will eventually shape the technical frame, organization and environment the network will include. Following are the intended design, features and functionality ELDIS is expect to include and fulfill.

The accurate design the network's mobile unit will possess is not yet clear for the ELDIS consortium. Among some of them though are cellular phones (usable by all), small generic hand-set radios (usable by care-providers), beeper (care-providers), transmitters and sensors integrated in a watch or bracelet (care-receivers), etc., to be used alternately according to the user's situation. Other design features like size and weight will also be specified after a series of studies like this one have been concluded. On the other hand, the ELDIS consortium already proposed some of the main functions the system will incorporate. These functions are primarily based on the user representations of health care providers' and receivers' needs alternately.

Among some of the functions, localization and emergency response, and a 2-way speech link³⁸ with the control center are included. The system will also include different, complementing basic units expected to function as denoted below³⁹:

- Monitor and Track Unit (MTU)

This unit is expected to be a small portable transceiver with an omni-directional antenna carried by the care-receiver and with the ability of sensing the user's medical parameters, sending and receiving emergency messages, and; locating by measuring range and searching out the user by measuring both range and direction.

- Searching Unit (SRU)

The searching unit is a portable medium sized transceiver with both an omni- and a directional antenna to be carried by the care-provider. It will include message display and a "friendly men & machine interface"⁴⁰ (MMI) for sending and receiving emergency messages from the MTUs, and monitoring MTU's range to search and locate them.

- Supervision Unit (SPU)

The SPU will be a fixed home-based transceiver with an omni-directional antenna and an optional directional one. This unit is to be installed at homes or institutions providing health care. It will work similar to the SRU, with the exception of direction measurement capability. Various SPUs will form a local wireless network expected to provide increased security for its users.

The three units will also possess a set of standard technical specifications each, such as, a data transmission rate of 20-100 Kbps, message length capability between 128-256 bits, data and distance differential coding, data and distance correction capabilities, and range- measuring accuracy between 20-30m⁴¹. The three units above will be used to implement various system configurations consisting of portable (mobile units described above) and fixed units (such as computers, satellites, telephone operations) using wireless links⁴². These are:

- A fully portable and stand-alone system: this is a system consisting of at least one SRU monitoring one or more MTUs. This system will be fully portable and is expected to provide

³⁸ Two-Way speech link means here the capability of the system to communicate both ways (care-receivers to care-providers and vice versa)

³⁹ ELDIS: Full Project Proposal; 2000, p. 4

⁴⁰ As stated on ELDIS: Full Project Proposal; 2000, p. 4. The commission does not clarify though what they infer by "friendly MMI".

⁴¹ As enumerated on ELDIS: Full Project Proposal; 2000, pp. 4-5

⁴² ELDIS Full Project Proposal; 2000, p. 5

remote medical supervision, specific perimeter monitoring functions, personal supervision and two-way messaging and search capabilities in emergencies. The operating range of this system will vary between several hundred meters to 1-1.5 KM, depending on the terrain. The main objective of this system construction is to provide care-providers (family members included) with the ability to supervise elderly and disabled, and to locate them in case of emergency.

- A Stand-alone home based system: this system will consist of a SPU installed in the user's home to monitor one or more MTUs in order to provide remote medical supervision. It will also allow monitoring functions, and emergency & normal two-way messaging in the costumer's home or health care institutions. In emergency cases the SPU will automatically give alarm to a central security monitoring facility for the nearest SRU to search for the MTU in distress.
- A stand-alone local area system: this third system will consist of several SPUs installed in a local area to monitor MTUs within the covered area. This configuration will provide the same functions as the other two. In addition, it will allow absolute localization of a specific MTU by calculations measured from three or more SPUs to that specific MTU. This processing unit consists of a workstation connected to the installed SPUs in the area. The SPUs will also form a wireless data network capable of transferring messages between any two points. This system is said suitable to provide care-receivers with protection services and independent living in small communities by assisting them in their living facilities, nursing homes, etc. Adding extra SPUs to meet different requirements can expand the areas covered by this system.

According to described system configurations and use, a mobile social alarm network like ELDIS has the potential to give its users a certain amount of mobility and autonomy within a specific area and range. By including technical properties capable of 24 hr. monitoring and registering of the target users' medical parameters, the system's communication center can hence detect their geographical position to supply assistance in case of emergency. In practice though the needs this type of technological development is expected to fulfill, can come in conflict with- and provoke conflicts among established conventions in legislative processes and decisions like data and privacy protection, improvement of health care services and decreasing health care related costs. Policy makers and their legislation processes and decisions affect –even though seemingly indirect- not only the possibilities for development of new technologies and technological networks like ELDIS but their design, features, functions, implementation and even acceptance in

the specific society they represent. The following section thus draws attention to the different health care policies in the Netherlands whose actions and decisions has motivated the proposal of – and will influence the future development of this technological network.

Dutch Health Care and Home Care Policies: Containment or Expansion for ELDIS?

Health care in the Netherlands is defined to include medical services as well as related support and social services. They range from medical care, mental health care and home nursing, to prevention and treatment of alcohol and drug abuse⁴³. Like any other system, the Dutch health care system is conformed of various actors. Among them can be found different groups of patients, several categories of providers –single professionals and institutions- and government agencies & administrative bodies⁴⁴. According to Schrijver, this system also includes a wide variety of services provided in hospitals, in specialized institutions, by ambulatory care facilities, and by independent professionals.

Alike other Western societies, the Netherlands has experienced a process of individualization that has caused family connections and relations to be lost or weaken. An example of this is the fact that children today rarely take their aging parents home with them, while parents of handicapped children often entrust their care to professionals⁴⁵ making it necessary for these individuals to be either hospitalized or admitted in institutions specialized on their care. As positive as it may sound though, this trend has not arrived without consequences. Among the consequences brought by this trend are excessively and ever-increasing high levels of health care costs and limiting care

⁴³ Schrijvers; 1997, p.15

⁴⁴ Schrijvers; 1997, p.15

⁴⁵ Bangma; 1998, p. 35

accessibility, particularly concerning hospital care and primary health care⁴⁶. As response to the above developing trend, the Dutch government desires to promote increasing “home care” services. Home care is defined by the National Council for Public Health (NRV, 1989) as: [the aggregate of care, nursing, treatment and guidance carried out by means of self-care, umbrella care, volunteer work and/or (additional) professional care aimed specifically at enabling the person in need of help to maintain himself within the home environment]⁴⁷. “Self-care” and “umbrella care” are understood by the council as the simplest and cheapest form of home care services by enabling family members, relatives, friends and/or neighbors have the primary responsibility of providing for the required assistance. In cases where this help is not available then voluntary care becomes the next best possibility.

In the Netherlands, the number of people supplying informal care for more than a year has long ago exceeded one million, turning formal care into a smaller sector within home care⁴⁸. To top it all, the increasing interest of private health insurers has led to the establishment of a growing number of commercial (private) nursing agencies, which enter a contract with the person in need of care and at times even do business directly with the insurer⁴⁹. The implementation of widespread home care services in the Netherlands was initially intended to assist handicapped and chronic patients. But, as the structure developed, the target groups were expanded to include elderly people, terminal patients, and people in need of extra -either temporary or permanent- assistance after surgery or accident⁵⁰. The expansion of the consumer sphere has forced distinctions between the different types of home care. Firstly; general home care, it consists of the

⁴⁶ Bangma; 1998, Schrijver; 1997, Coolen; 1993

⁴⁷ Bangma; 1998, p.36

⁴⁸ Bangma; 1998, p.36

⁴⁹ Bangma; 1998, p. 37-38

⁵⁰ Bangma; 1998, p. 38

joint help supplied from key-disciplines, i.e. regional nursing, family care, family doctors and general social work, supplemented by other disciplines such as physiotherapy. This type of care is to be temporary and non time-intensive. Secondly; is the so-called intensive or supplementary home care consisting of specialized care for a longer period of time. This type of home care is more time consuming and demands the employment of several disciplines and expensive aids like nursing aids, adjustments at home, etc⁵¹.

Approximately 10% of all forms of care in the Netherlands is (by 1996) funded for from national public funds, leaving approximately 80% of the costs to be covered by private insurers and around 10% by the patients themselves. In regards to public funding, the country distinguishes between “normal” medical expenses and exceptional costs associated with long-term care or other expensive medical treatment, where burden cannot be assumed by the individual or (private) insurance⁵². To support expensive medical costs, a compulsory national health insurance plan, the Exceptional Medical Expenses Act (AWBZ) has been implemented. Funding is covered by an also compulsory premium collected through income tax, which everyone – whether a wage earner or not- must pay. Every person living in the Netherlands and subject to Dutch income taxation is covered by this act. The benefits include long-term residential and nursing care for the elderly, full psychiatric care, home-based care and full care for the physically and mentally disabled⁵³. For “normal” medical expenses, insurance under the Social Health Insurance Act is regulated. Everyone meeting the requirements appointed by law is automatically insured and must pay the required premiums and contributions plus a fixed flat rate premium for about 180 dollars yearly. The benefits of this package consist of regular medical treatment, i.e.

⁵¹ Bangma; 1998, p. 39

⁵² Schrijver; 1997, Bangma 1998

hospitalization, general and specialized medical-care, physical therapy, dental care for youth, etc, and care not covered by the AWBZ. In addition to this funding, individuals earning more than 35,000 dollars, self-employed individuals, and owners of small independent businesses have the option to acquire private health insurance. The standard benefit package is almost the same as the one offered under the social health insurance act described above but individuals may choose among other coverage packages, the premiums varying accordingly⁵⁴. This final means of funding is being promoted throughout the different OECD countries. This trend aims towards making the consumer (patient/user) assume more responsibility for health care costs. This is so primarily for economic reasons in order to shift the financial burden from the collective sector to the private individual and to make the consumer of care services more cost-conscious reducing as a result the demand for- and volume of care⁵⁵

This has been the situation in the Netherlands since 1996⁵⁶. The aspects of the Dutch health care system discussed in this section demonstrate that creating an organizational infrastructure for ELDIS and its facilities include not only a wide range of services, but also collaboration and relationship-building in/with diverse institutions, organizations, policies and technical facilities, which are themselves in constant change as well.

As mentioned in the prior section, policy makers and their legislation processes and decisions affect the possibilities for development of new technologies and technological networks like ELDIS in the form of promoting or hindering specific designs, features, functions,

⁵³ Shrijver; 1997, pp. 27, 164

⁵⁴ Shrijver; 1997, p. 165

⁵⁵ Shrijver; 1997, p. 165

⁵⁶ Schrijver; 1997, p.166

implementation and even acceptance in the specific society they represent. The following section thus draws attention to the interpretation and use of two other policies in the country whose influence can affect the overall development of and decisions for the ELDIS network. These are policies in regards to Dutch citizen's right for privacy protection known in Dutch as WbP or Personal Data Protection Act (2000) and WGBO or Medical Contract Bill (1995) respectively.

Privacy Legislation in the Netherlands

As we can deduce from the technical specifications presented above, the functionality and services expected to be comprised in this technological system, even though proposed to sustain the latest reforms in health care policies in the Netherlands, diverge from other policies in the country. The clearest divergence in this case, appears between policies developed to improve health care provisions in the country and those attempting to sustain the right of privacy each individual citizen is entitled to as proclaimed by the Personal Data Protection Act (WbP) and the Medical Contract Bill (WGBO) respectively.

“Of all human rights, privacy is perceived as perhaps the most difficult to circumscribe and define⁵⁷. In its narrowest sense, some might think of it as no more than a luxury for the better-off...At its widest, it can connote the last opportunity for the poorest and weakest human beings to defend themselves against ever-encroaching pressures of the power groups in their societies which are forever pushing inwards the boundaries within which those unique individuals can take refuge, and ultimately ‘be themselves’⁵⁸.”

In spite of the fact that an infinite amount of theoretical arguments, opinions and analyses over the definition and use of privacy have been raised and given, the discussions around the conception and boundaries of this right continues. The purpose of this section though is not to follow them or start a new discussion around the term but merely to chart the use of privacy as

⁵⁷ Privacy and Human Rights...; 1994, p.1

specifically legislated for in the Netherlands, in light of recent developments in information and communication technologies like ELDIS. The discussion around how specific articles in the laws could come in conflict with technological features, design or uses prescribed for ELDIS will be given first in Part III with the scenarios.

As mentioned earlier, legislation of privacy in the Netherlands appears in the form of the WGBO promulgated in 2000 and the WbP in 1995. The Personal Data Protection Act (WbP), 2000 derives from the promulgation of Directive 95/46/EC of the European Parliament and of the Council of the European Union of November 1995 on the protection of European individuals with regard to the processing of personal data and on the free movement of data (OJ L 28 1)⁵⁹. Even though the Constitution of the Netherlands did not include a general right to privacy until 1983⁶⁰, the country has come a long way ever since, especially after entering both the European Community and the Council of Europe. The actual WbP derives from OECD's guidelines governing the protection of privacy and transborder flows of personal data.

Among the Act's general purposes are establishing basic rules for data protection measures to be sustained by both public and private sectors, setting out special rules about transborder data flows, and establishing mechanisms of consultation and supervision as well as enforcement⁶¹. In the Netherlands, the Act intends to regulate the processing of personal data to shield its citizens' in general to ensure that personal integrity and privacy are not infringed or invaded. It applies specifically to the fully or partly automated processing of personal data (computerized), and the

⁵⁸ Privacy and Human Rights...; 1994, p.1

⁵⁹ As specified on unofficial translation of (Dutch) Personal Data Protection Act (Wet bescherming persoonsgegevens) of 6th July 2000. Document found at: http://www.registratiekamer.nl/bis/top_2_6.html

⁶⁰ Privacy and Human Rights...; 1994, p. 62

⁶¹ Light will be shed when necessary on specific articles throughout the scenarios in Part IV.

non-automated processing of personal data entered -or intended to- in a file⁶². In this sense, conditions to be followed by the parties involved for the lawful processing of personal data are prescribed. Among these conditions are specific prohibitions on the processing of personal data concerning a person's religion, philosophy of life, race, political views, nationality and health. Chapter 2, Section 1, Articles 6 through 15 set out the basic principles of data protection in the country. According to these principles -in short-, data experiencing automatic processing should be⁶³:

- (a) obtained fairly and lawfully;
- (b) stored for specified and legitimate purposes;
- (c) adequate, relevant and not excessive in relation to the purposes for which they are stored;
- (d) accurate and, where necessary, kept up to date;
- (e) preserved in a form which permits identification of the data subject for no longer than is required for the purpose for which the data is stored.

A Data Protection Commission has been established to supervise both, codes of conduct developed by organizations as well as to supervise, when necessary, that the processing of personal data occurs according to the basic principles above in order to prevent unauthorized disclosure.

In regards to processing special data like personal health data, it is forbidden to process such data unless otherwise stated on the respective article in the Act. In cases where allowed, the Wbp orders an additional control of the correctness of processing personal health data in addition to processing the data accordingly to the norms posed for that of all/any kind of personal data⁶⁴. The WbP sets forward a number of basic rules and principles governing lawful processing of personal

⁶² As stated in the act. Registratiekamer's unofficial translation; www.registratiekamer.nl/bis/top_2_6.html

⁶³ Michael; 1994, p. 36

⁶⁴ Peeters; 2001, p. 28

data in general. These rules concern in short⁶⁵:

(a) Reporting the processing

The processing of personal data must be reported in advance to the Data Protection Board or a privacy officer, unless processing has been exempted.

(b) Transparent processing

The person involved must be able to see who is processing his/her personal data and for what purpose.

(c) “As required” processing

Personal data may only be collected for specific, explicit and legitimate purposes and not further processed in a way incompatible with those purposes.

(d) Lawful basis for the data processing

The processing of personal data must be based on a foundation referred to on the WbP, such as permission, agreement, legal obligation, justified interest and the likes. For special data such as health, stricter limits exist (WGBO).

(e) Data quality

The personal data must be as correct and as accurate as possible, sufficient to the point and not excessive.

(f) Rights of parties involved

The parties involved have the right to take cognizance of and to improve their data as well as the right to raise objections.

(g) Processing personal data by a processor

If processing is done by outsource, it must be ensured that s/he will observe the instructions of the person responsible.

(h) Protection against loss and unlawful processing of personal data

Suitable technical and organizational measures must make up for lawful processing. WbP requirements must be implemented efficiently in any organization processing personal data in order to provide support to the citizen's right to privacy.

The Wbp deals in general with the processing of various types of personal data, rather than with

registration of this data in specific sectors. Besides the Wbp, specific legislation for the

registration of health data exists in the Netherlands in the form of the WGBO (1995) or Medical

Contract Bill found in the Dutch Civil Code. The WGBO is the most important act with regard to

⁶⁵ Based on <http://www.registratiekamer.nl>

specific individual basic rights. Its directives focus on the sustenance of compulsory health care consumers' individual basic rights; the so-called patient rights. It intends to regulate the use and disclosure of personal data recorded within the health care sector (medical secrecy)⁶⁶. The WGBO regulates the relation between doctor and patient, by controlling care-provider or care-providing facilities' agreements with patients, making the relation as equal as possible. Several rights and duties apply to both the provider and the patient and these mutual obligations are specific and binding on the both. Its main objective is to ensure the presence of legal circumstances for a good cooperation between the different parties involved⁶⁷. The Bill explicitly lays down medical secrecy⁶⁸, as a patient's inalienable right by emphasizing that information can only be given to a third party on the basis of patient consent and legal regulations⁶⁹. It centers its directives in four main clauses. These are⁷⁰:

(a) Consent

Although the provider is responsible for the content of the services and any risks involved it is up to the patient to agree with or refuse the recommended therapy. Treatment can hence only be started with the patient's consent and the provider must accept the patient's decision. Consent may be stated orally but it is compulsory for providers to note the consent in the medical record.

(b) Information

It is the provider's responsibility to present the patient with necessary information (i.e. therapy nature, risks, possible side-effects, probabilities for success, alternative therapies) needed for therapy in an understandable manner. Even though the way to accomplish this is not given consent and information form the basis of what is known in the field as informed consent. That is: No therapy without consent, and no consent without therapy.

(c) Medical Record

Providers must maintain reliable patient medical records. The record must contain all the details related to the patient's therapy: history and physical, diagnosis, test results, correspondence, etc. Albeit the health care practitioner administrates the medical record, the patient has an unlimited right to inspect his/her medical record and a copy must be provided to him/her on request. The record must be kept for ten years.

⁶⁶ Peeters; 2001, pp. 27-28

⁶⁷ Peeters; 2001, p. 28

⁶⁸ Consisting of an oath to secrecy and the right of nondisclosure of medical information.

⁶⁹ Peeters; 2001, p. 30

⁷⁰ Schrijvers; 1997, pp. 231-232

(d) Privacy

Personal details about patients must always be handled carefully. Information to third parties may only be released with the consent of the patient. In relation to patients right to privacy in institutional health care settings, the act stipulates that medical consultations must take place in separate rooms out of the view and earshot of others.

The WGBO also specifies that it is the patient's duty to give the provider clear and complete information enabling the provider to make a diagnosis and offer treatment accordingly. Patients are also supposed to follow advice to a "reasonable extent"⁷¹. The WGBO is a sector specific law centering on personal data recorded and dealt with specifically in the doctor-patient relationship. It provides general guidelines (non-detailed contract) about both parties' rights and duties to improve communications between them. In situations where both laws are valid in regard to certain personal medical data, the law offering the individual involved the best protection will be prioritized. In cases where conflict still exists, then the most specific law will precede over the other⁷².

Conclusion

Privacy sustenance in the Netherlands is represented in the form of the health care sector specific WGBO and the more general WbP. These policies are understood as central considerations for the decisions involved in the technological development of ELDIS. Taken into consideration they are considered by the network's developers to guarantee the successful design, use and implementation of ELDIS. However, as has been stressed throughout this chapter, decisions in regards to technological development cannot be made alone on the basis of specific considerations like privacy sustenance in this case. The interactions among the other factors

⁷¹ Schrijvers; 1997, p. 232

⁷² Peeters; 2001, p. 28

mentioned in this chapter must also be considered and dealt with. Even though not directly discussed here, cultural values and power distribution are not only embedded on the country's different policy-making experiences and process but will also become embedded in ELDIS developmental phases and finally on its organizational structure. These aspects hence become relevant too in the determinants to be considered in relation to the development and establishment of technological development in general and more specific for the Dutch health care system in the form of ELDIS.

In this chapter the background surrounding, and motives behind the proposition to develop a technological network like ELDIS have been presented. After the necessary connections and clarifications were done, different potential constituents, determinants and representations have been charted and discussed. The intention with this chapter has been to open for an easier understanding of the issues to be developed and analyzed in the next chapter by portraying an overall view of what will constitute the ELDIS network. Part III hence intends to in the form of scenarios, foresee and describe potential situations experienced by specific users and actors involved in the network, which could cause dilemmas in regards to a specific design, function and use of ELDIS and privacy sustenance in the Netherlands.

Part Three

Scenarios on the Social Shaping of ELDIS in Relation to Privacy Sustenance as Dictated by Dutch Legislation

Introduction

As has been mentioned in the previous chapters, the Netherlands is targeting health care policies towards increased home care for the elderly and disabled. The objectives with these reforms is to increase the effectiveness of the country's social provisions, as well as to reduce rising health care costs, particularly those connected to long-term care of the elderly. Governmental policies have hence initiated a process of diffusion of organizational, financial and technological innovations -which ELDIS is part of- as part of the strategies to achieve the above-mentioned aims. Because of the increased focus on the elderly population's consumption of care provisions in the Netherlands and their position as target groups in the ELDIS network, they have been chosen as focus for the user scenarios depicted in this chapter. Among the elderly population Alzheimer sufferers have been chosen as main user- representations in the scenarios. Each scenario intends to portray one of many potential situations appearing with the use of the ELDIS network. The comments addressed after each scenario will be organized with reference to various moments in or elements of the experience. The discussions' main objective is to address specific privacy legislation issues, which could rise from the perspective and experiences of the actors -on one side- and specific uses and functions of the device -on the other. The overall discussion on how different relations appearing at different times and in different spheres can affect the service provisions intended for the network will be discussed in the concluding section of this chapter. But, before presenting the scenarios, recent available statistics on elderly and disabled consumption of health care services and Alzheimer figures in the Netherlands are provided.

Why ELDIS: Increasing Problematic on Consumption of Health Care Provisions by Elderly and Disabled in the Netherlands

Even though care for the elderly in the Netherlands conforms only one component of health care as a whole, compared to the rest of the population, the elderly makes a significantly extensive and intensive use of health care provisions than other members of the population⁷³. Table 3.1⁷⁴ below presents the total provision expenditure by the elderly in the Netherlands (in Guilders) and the proportion of these expenditures compared to other groups in the Dutch society.

Table 3.1 Health care in the Netherlands in 1990: (a) total provision expenditure in billions of Dutch guilders and (b) proportion of expenditure incurred by the elderly (global figures)

Provisions	(a)	(b)
extramural care	8.6	±45%
° home help	1.8	±70%
° home nursing	1.0	±75%
° general practitioners	2.0	±40%
° other sectors (dieticians, dentists, etc.)	3.8	±25%
intramural care	9.0	±97%
° homes for the elderly	4.8	±99%
° nursing homes	4.2	±94%
hospitals and medical specialists (excluding psychiatric hospitals)	16.1	±45%
mental health care (extramural and intramural)	3.3	±15%
medicines and technical aids	4.0	±10%
prevention and other sectors	4.7	±25%
TOTAL	48.9	±40%

Source: Ministry of Health, Welfare and Cultural Affairs, 'Financieel Overzicht Zorg', 1991.

As table 3.1 shows, elderly over 65 produce an average 40% of all financial health care expenditures even though they only form 13% of the population. In 1990 the elderly population numbered around 900 000 and by the year 2030 that number is expected to grow to 1, 700 000⁷⁵.

As a result, a relatively large share of health care costs is related to the elderly. Hospital admissions for instance, are twice as high for individuals over 65 than for those between 25-44

⁷³ Coolen; 1993, p. 23

⁷⁴ Coolen; 1993, p. 24

years of age⁷⁶.

In the case of disabled individuals, various attempts have been made in the Netherlands to compile a list of the number of disabled persons. Due to practical (difficult to access which disabilities and to what degree should be registered) and especially ethical objections (mostly relevant for policy-makers), no registration is maintained⁷⁷. It is however estimated that 10% of the Dutch population has some type of long-term disability. The disabilities registered are mostly related to functional impaired disabilities and have been divided into six categories: limited walking function, limited arm or hand function, visual disability, auditory disability, limited stamina and, disturbance of equilibrium⁷⁸. Among the percentage of Dutch population classified as having a disability, the elderly are once more over-represented in this category. 1979 (no recent data found) figures show that 37% of disabled individuals are over 65 years of age. As is well known by now these figures are expected to be even higher today and will continue to increase within the next 30 years⁷⁹.

The innovative policy of the Ministry of Welfare, Health and Cultural Affairs opens for a diversity of measures to achieve the changes proposed for health care in the country. Amid these measures is research in and development of technological systems like ELDIS, which could both: enable the individual's monitoring and assistance to restore mobility, independence and autonomy of life and, reduce the country's rising care costs.

⁷⁵ Schrijvers; 1997, p. 102

⁷⁶ Coolen; 1993, p. 23

⁷⁷ Schrijvers; 1997, p. 110

⁷⁸ Schrijvers; 1997, p. 110

⁷⁹ Coolen; 1993, Schrijvers; 1997, Prodi (speech of November 1999)

As stated earlier, technological solutions like ELDIS can in theory solve these dilemmas. But, when set into practice the intended functionality and use of such systems are often rendered futile due to unforeseen and/or unconsidered relations and circumstances by actors in charge of developmental and implementational phases. It is in regard to accessing and discussing these relations and situations that the scenarios below have been created. The intention with the creation of the scenarios is to evaluate eventual privacy issues rising with the use of ELDIS in base of the system users, the different actors, and, potential external/internal factors involved – among which policy-makers and privacy legislation are to be found. The scenarios intend to portray real-life conditions, situations and experiences confronted by individuals suffering from dementia⁸⁰ caused by Alzheimer (AD)⁸¹. Individuals suffering from AD have been chosen as representatives for ELDIS' target users in the scenarios for the following reasons:

- Globally, Alzheimer is the most common cause of dementia (over two thirds of all dementias are attributed to AD⁸²).
- Some of AD sufferer's needs are similar to those of other mentally and/or physically disabled individuals in general (AD is also accompanied by physical disabilities and symptoms i.e. cardio-vascular problems, anemia caused by weight loss, etc.), making the representation of target users for the ELDIS system more comprehensive.
- In early stages AD sufferer's needs are in general representative of those needs of the elderly population (75 and over).
- They represent as well the needs of younger individuals suffering from either Alzheimer or similar dementia-causing diseases like Aids, Parkinson, Huntington, etc. (In 10-20% of Alzheimer's disease cases the first symptoms become apparent before the age of 65 –known as pre-senile Alzheimer's disease)⁸³.
- The largest application for ELDIS as described by the IRV is individuals with mental disabilities, in particular elderly suffering from dementia caused by Alzheimer.

As the figures in this segment present the increased growth of the elderly population has caused

⁸⁰ Dementia refers here to the range of symptoms commonly found in people with brain diseases, which result in the damage and loss of brain cells causing deterioration of the person's mental and behavioral functioning

⁸¹ For factual figures on AD in the Netherlands and clinical facts on the progression, symptoms and treatment of the disease see appendix 3.

⁸² According to figures from the International Alzheimer Research Foundation (IARF). See also www.alzheimer.nl/EARS.htm

⁸³ According to statistics presented at The European Alzheimer's Research Symposium of September 17 1999 organized by IARF. See also <http://www.alzheimer.nl/EARS.htm>

policy-makers to already now worry about how to control continuously rising care costs especially in the future, in addition to supply for the demands of this group on the Dutch health-care system and society. Having made these figures clear, the scenario representation for the ELDIS network, are depicted below.

Scenario Representations for ELDIS: A Technological Network in Use

About the Scenarios

The scenarios created below are based on interviews with key individuals from the Dutch Alzheimer Foundation and informal conversations with medical doctors⁸⁴, as well as relevant medical and social literature for the cases described. The Dutch Alzheimer foundation was chosen as interview candidate because of the organization's extended knowledge on and experience in representing individuals suffering from any type of dementia besides Alzheimer. The Dutch Alzheimer Foundation is a non-profit organization established 14 years ago to represent their client's needs and rights in society, as well as to provide information and support to the patients and their families. The individuals interviewed range between the functioning administrative director, professional care-providers (nurses) and volunteers. The focus of the interviews⁸⁵ extend from how they experience the workload of nursing and caring for patients with dementia, to, who should be regarded in the decision making process for providing health care services for these individuals, and their view on technologies developed with this purpose. Because the interviewees represent patient and family member's rights and needs, and because of time-related procedures connected to the Dutch Ethical Commission's granting permission to interview family members of AD sufferers, was directly done to health care consumers in the

⁸⁴ Focused on the clinical facts of the disease. These conversations took place in Norway with Norwegian Medical Doctors.

Netherlands. Conversely, informal conversations on patient's needs and care in general took place with a medical doctor with experience in treating patients suffering from mental disorders and personality changes due to AD, cerebral tumors and traffic accidents among others.

As mentioned before, the scenarios intend to depict specific situations in relation to the potential development of the ELDIS network. As requested by the IRV, the assessments on each scenario focus wholly on Dutch privacy regulations namely, the WGBO and the WbP. It is important to stress though, that however inherently consistent with real-life situations depicted, the scenarios may not necessarily occur as described below. They are developed to "broaden the field of vision"⁸⁵ in face of technological development, on top of to encourage the commissioners of this thesis to the realization that expectations -because of other uncertainties irrelevant for this study- can develop differently than planned.

Three different scenarios have been created to emphasize the interactions and relations appearing within networks like ELDIS and how they can affect each other. The first and second scenarios are based on sociological factors like different type of users, actors and representations involved in the network. The intention here is to assess possible privacy issues rising when decisions within the network are based on specific users and actors alone and how the relations and interactions with each other could affect the overall performance of specifics of the network. The third scenario focuses on technological factors like a specific design or function of the technology at hand and how this specific design or function can raise privacy issues and hence affect the intended care provisions of the network. The first scenario is specifically based on John's

⁸⁵ See appendixes 4 & 5

⁸⁶ Brouwer & Schreuder; 1996, p. 64

experience as an Alzheimer patient in the network's relation, specifically towards the artifact. The second scenario is then based on the experiences and relations between network-supporting actors like data-managers and administrators; other potential users like nurses and patient organizations and potential privacy issues rising within their relation to the technological artifact. After the sociological factors have been given as point of departure, the third scenario will focus on the technological factors. This scenario focuses on possible privacy policy issues rising from decisions based on a specific design, use and function of the technical artifacts in the network.

Scenario One

User /System Relations: John 74 has Alzheimer and Wanders

This scenario seeks to portray one of many potential situations appearing on implementation of the ELDIS network. Based on John's needs, capabilities and well-being, it intends to shed light on possible privacy issues appearing with the services rendered by this tracking and tracing network. In this sense, it is necessary to clarify that even though it is difficult to draw an accurate picture on how dementia gradually affects the sense of well-being of a person, well-being is usually related with fundamental human rights such as self-determination, freedom and privacy to maintain integrity and dignity. Even though such rights are as essential as privacy issues to maintain -in this case- mentally and physically disabled individuals' integrity and dignity, they will not be discussed here. The focus here lies solely on potential legislative privacy issues rising with the service provisions the ELDIS network offers its user John, based on his limited capabilities and specific needs:

John is a 74-year-old lively and cultured widower living in Amsterdam. He has recently been diagnosed with Alzheimer, after his daughter Marion noticed peculiar changes in his demeanor. He had turned from normally being a well-put, independent and organized person, to not caring for his looks, insecure and at times even aggressive. He tends to forget where he put things, has

problems remembering names, faces and places, and has lost some weight. For Marion, John seemed older and frail. He had also been found several times wondering around the neighborhood. When asked, John could not even remember where he was heading for in the first place

After being diagnosed with AD, and knowing how the disease progresses, John agrees to move to a home care facility near his daughter in Rotterdam. But, because of the large demand for nursing homes and lack of availability in the city, John was obliged to move in with Marion, her husband and their two-year-old son.

The last months since John moved in with the family have proven too hard to handle for Marion. Her father does not recognize her or other family members during prolonged intervals. He increasingly suffers from insomnia and has now taken to wondering in the long hours of the night. In addition, he needs constant supervision to monitor normal daily routines like eating, bathing and dressing. He seems to have forgotten even simple everyday routines like brushing his teeth. He constantly regresses to past experiences and acquaintances. What worries Marion the most though are his sudden aggressive outbursts towards help, the hallucinatory episodes and his constant blaming family and friends of stealing his belongings. The family has become strangers to him and is treated with skepticism and suspicion. Marion feels frustrated and does not know what to do.

Marion has found support through the Dutch Alzheimer Foundation's local chapter. A volunteer comes for a couple of hours from Monday to Friday, allowing Marion some free time to run errands and spend time with the rest of the family. She enjoys this extra support, the volunteer has experience working with patients suffering from dementia, is patient with John and understands his needs. Marion feels understood and supported to some degree. Many of her questions have been answered but she is in need of a long-time solution to the family's situation.

Through the volunteer, John has started a trial program for a recently developed network established for elderly and physically/mentally disabled individuals. John stays home alone now for most of the day. The technology used in this network allows John's all moves to be monitored 24 hours a day within a specific ratio by means of a monitoring and tracking unit integrated in John's wristwatch. They have chosen a wristwatch as the design of the monitoring device over the mobile phone -among other devices- because they feel it best adjusts to John's condition. They are worried that with a different type of device, John will wonder off without having it with him. The wristwatch is built so that John is localized through the signals sent by the watch to the satellite. The wristwatch is also suited with a panic alarm button in case John needs assistance in other circumstances besides wondering. In case of an emergency, all John needs to do is press the panic button and an alarm goes off on the nearest monitoring center within seconds. However, the wristwatch offers a disadvantage over a design like the mobile phone. Contrary to the mobile phone, the wristwatch does not integrate the possibility for a two-way messaging system allowing John direct-speech contact to the operator, this leaves him without the possibility of verbally communicating his needs and having hence to wait until help from the network arrives.

John has been part of the program for a while. Marion is in general satisfied with the services provided by the network and the technology used. John's position is promptly localized and she feels she needs-not worry about her father wondering off and getting lost because the system

satellite locates him at any time, and in any place or circumstance. Since starting the program, John has been found wondering several times. Last winter he was found sitting on a bench by the river in his underwear. A nurse summoned from the network arrived to take John back home. Informed of John's medical condition and limitations, the nurse handled John readily and safely returned him home after checking that he was not physically injured. Because of the prompt response of the network in locating him, John had no physical injuries other than being a bit cold.

Discussion for Scenario One

The symptoms depicted in this scenario are common for AD sufferers in stages I and II. These stages have been chosen as representatives for this scenario, based on the reactions and comments of the individuals interviewed from the Dutch Alzheimer Foundation. When asked directly where and when this type of network could be most helpful to AD sufferers, the individuals consistently stressed stages I and II. They referred to stage III as a passive stage where the sufferers are bed-ridden, making thus the use of a network like ELDIS irrelevant. They did underline though the increased need for monitoring and assistance of primal needs, but not in relation to wondering or detecting falls, which will compose ELDIS' main functionality.

When dealing with issues like mental disability caused by dementia, birth defects or accidents, one is tempted to begin with ethical questions related to identity, status or even ontology⁸⁷. Even though the ethical perceptions of humanity are not analyzed here, it is necessary to highlight these preconceptions because, at a conscious level or not, it is with them in mind that actions and decisions in society take place. We often ask ourselves how much do demented individuals matter and why? When asked, relatives of mentally disabled individuals due to dementia usually regard them as different persons. Comments like "this isn't the same person that I have shared...with", "s/he is not the same person s/he once was" or "the real John/Martha would have

⁸⁷ Binstock, R.; Post, S. & Whitehouse, P.; 1992, p.46. Ontology: The branch of metaphysics dealing with the theory of pure being or reality. As defined in The Cassell Concise Dictionary; Cassell, 1997

never agreed to...”. These statements are often related to our conceptualization of humanity. Society bases being “human” mainly to an individual’s rational ability and the ability of being moral agents capable of taking responsibility for our choices and acts⁸⁸. This definition suggests then that individuals who have lost, who have a limited or, who never have had this ability are less- or non human, and hence count less than, or have a different status than. Because of these pre-conceptions, people with dementia belong amongst the most vulnerable groups in society. Their fundamental human rights i.e. right to self-determination, freedom, integrity, privacy, and needs, must constantly be assessed, protected and reinforced. Particularly, where their condition is so deteriorated that they may no longer be able to make decisions by themselves, or understand the extent of or consequences the decisions may have in their daily lives. It is indisputable for healthy individuals that everyone has the right to decide how to lead their life especially in relation to intrusion of privacy. However, when referring to people with mental disabilities - because the outcome of the disease renders them dependant on others, and people’s attitudes towards the disease- the boundaries of self-determination become shady and unclear⁸⁹, affecting as well the boundaries of what is understood as freedom and privacy. As the health of dementia patients declines, those who love and care for them face making decisions on the level of life-sustaining treatment the patients should receive. Because dementia patients are incapable of making informed decisions over their own treatment and care, such decisions fall on family members, care-providers, and others. The standards guiding these alternative decisions can at times be too wide and confusing, antagonizing each other’s purpose, as is the case with the forces behind the development of a system like ELDIS, the users needs, and, the functions and design the system should include.

⁸⁸ Binstock, R.; Post, S. & Whitehouse, P.; 1992, p.46

⁸⁹ The legal rights of people with dementia: http://www.alzheimer-europe.org/lawnet2_short.html

In John's specific case, due to Marion's consent and the none invasive technology used to locate him the function and use of the technological device does not necessarily conflict with the country's established legal parameters on privacy sustenance as established on the WbP. Then again, it is necessary to stress that in the Netherlands, alike many other countries, privacy legislation is limited to informational privacy; that is, the mere processing (WbP) and recording (WGBO) of an individual's personal data. Other types of privacy such as bodily privacy⁹⁰, territorial privacy⁹¹, expressive privacy⁹² and accessibility privacy⁹³, even though considered as fundamental human rights in treaties like the Universal Declaration of Human Rights and the International Covenant on Civil and Political Rights, have consequently been taken for granted in legislative processes. But, it is in cases of individuals with mental and physical limitations like John, that the right for these types of privacy becomes increasingly violated. In this specific case, John's incapability of making decisions for himself or of communicating his feelings and/or desires, make him most vulnerable to violations on some of the other types of privacy rather than informational. Like John, individuals suffering from mental and/or physical disabilities often find themselves at the mercy of those making their decisions for them on the basis of what is believed to be "best for them" or their "well-being". But, the "what is best for" and "well-being" of people with dementia is more often than not connected to a society's general understanding of dementia. When negatively viewed, people with dementia are stigmatized and hence less supported in a society. Society often forgets that individuals suffering from dementia, alike healthy rational

⁹⁰ Concerns the protection of people's physical selves against invasive procedures. Banisar,D.& Davies,S.; 2000, p. 4

⁹¹ Concerns the setting of limits on intrusion into domestic and other environments such as workplace or public space. Banisar, D. & Davies, S.; 2000, p. 4

⁹² Concerns freedom from coercion and discrimination when making personal decisions such as free development of self-identity. Mohammed, E. A.; 1999, p. 2

⁹³ Concerns situations where information is sought in order to access the person in question (overlaps with informational privacy). Mohammed, E. A.; 1999, p. 2

human beings experience embarrassment and anxiety in specific situations, on top of depression and worry because of the disorienting chaos in their minds.

In the case of the WGBO, which, as mentioned earlier is a sector-specific law centering on personal data recorded and dealt with in the doctor-patient relationship, conflicts related to patient's rights (in this case users) can rise. The Bill explicitly lays down medical secrecy⁹⁴, as a patient's inalienable right. It emphasizes that information can only be given to a third party on the basis of patient consent and legal regulations,⁹⁵ and aims at regulating the relation between doctor and patient, by controlling care-provider or care-providing facilities' agreements with patients. It is within this directive that privacy related conflicts can rise for the ELDIS network. These conflicts are specially connected to the network's position within the country's health care provisions. ELDIS position in the system and within the doctor-patient relationship must be clarified before the implementation process begins. Will ELDIS be regarded as a third party organization or institution detached from the country's health care system or will it be defined as a care-providing facility created by the state for supporting ever-changing health care policies? In the case of the former, the ELDIS administrators must then file for permission to process their users data; particularly medical data to the appointed government entities in charge. Another possible issue rising is related to the possibility for cooperation between physicians and the network. An example of this has to do with the patient's right, to undisclosed his condition as well as to be kept uninformed of it.⁹⁶ In ELDIS' case, in order to supply better services and care⁹⁷, the network administrators may unwillingly force their clients into a situation where they and other

⁹⁴ Consisting of an oath to secrecy and the right of nondisclosure of medical information.

⁹⁵ Peeters; 2001, p. 30

⁹⁶ As stated in the WGBO.

⁹⁷ As stated in the WbP Article 8 sections b,d & f.

are informed of their condition. Supported by Article 8, Sections b, d and f of the WbP⁹⁸, the network can in a contract and as part of the conditions for service provision, force its target users to disclose some of their personal information. This itself forces the user to become informed of his/her condition, even when not desired, conflicting with the patient's right to choose not to be informed of his/her condition -as stated on the WGBO-. Situations like the above, clearly can cause clashes between the two directives aiming at protecting Dutch citizen's privacy. It is essential to stress here though that in situations where both laws are valid in regard to certain personal medical data, the law offering the individual involved the best protection will be prioritized. And, in cases where conflict still exists, then the most specific law will precede over the other⁹⁹. What is unclear though is who makes this decision and what premises are considered in the process of making the decision.

As mentioned earlier, the scenario depicted above intends to portray the potential benefits a network like ELDIS can provide for its target users, given that their personal data is handled and processed as stated on the country's privacy regulation acts. If the procedures established on the WbP and WGBO respectively are followed as stated in the acts, the development of this technological network could provide its primary users the chance to be cared for at home as long as possible,¹⁰⁰ as it simultaneously relieves their family members and friends of the physical, emotional and psychological burden long-term caring imparts. Nonetheless, through the scenario it becomes clear that issues rising from privacy regulation alone can- and will not supply the proposed user-benefits expected with the development of ELDIS, nor will they support in totality, the changes proposed on the country's health care policies.

⁹⁸ Here the conditions and circumstances for the processing of personal data are described.

⁹⁹ Peeters; 2001, p. 28

Scenario Two

Actor/System Relations: Services and Provisions are Outsourced

Issues rising from privacy regulation in the Netherlands in relation to the target users, is just one piece in the puzzle forming part of what constitutes the ELDIS network. Other issues rising can range between pre-conceptions over the diseases, the target user's capability for learning how to use and using the technological device, administrative and economical jurisdictions. These issues can and will rise because of the various interactions and interchangeable interests occurring between the actors and relations in the network. Privacy regulation issues in the Netherlands do not necessarily rise regarding the technology used for localizing the network's target users, but can rise regarding other actors and functions, as will be demonstrated in the next scenario:

ELDIS' acceptance has been successful already in an early stage. Because of the promising potential for relieving primary¹⁰¹ care-providers of the burden of caring for their family members, the network has had a larger reception than first expected. This success has caused the network's infrastructure to become overloaded and hence incapable of supporting the target users as desired and planned. Among the overworked in the network are the professional care-providers, (i.e. nurses and ambulance drivers) and the receptionists at the monitoring centers. On various occasions, clients have had to be assisted by either the nearest police officer or fire department available, and, at times, even by volunteers of organizations representing the patients. The lack of sufficient specialized personal to further support the network has augmented the need for outsourcing at various levels within the network, in order to support and extended the service provisions expect from ELDIS. The specific service-outsourcing need has itself caused an increasing necessity to enlarge the already existing client files in addition to make it available to other parties supplying assistance. To achieve this, the ELDIS administration has decided to build an automated database where the client's needs and capabilities, among other things, are registered.

To fulfill the expected services, the database must be computerized and capable of automatically providing the users' essential medical information to the person summoned to assist them. Because of the unpredictability of the target users, the system should also be designed so that it is possible for them to download the client's medical data at any time, any place and in any given circumstance. The register must provide accurate and fulfilling data on the target user's age, diagnose, present condition, symptoms, treatment and type of medication and usual dosage, as

¹⁰⁰ As stated in the recently revised health care policies of the country

¹⁰¹ See Part II section Dutch Health Care and Home Care Policies.

well as who to contact in case of emergency. To ensure accuracy and effectiveness, the data in the register is to be periodically updated as the disease progresses and new symptoms develop.

After a couple of months the completion of the automated database has not gone as smoothly as first expected. A large amount of both human and financial resources have been invested but have proven inadequate. In order for it to function as planned, extended resources are needed. To top it all, because of lack of specialists on the automation field within the network, the administrators have had to outsource as well the building of, maintenance and services of the database; condition, which has further increased the costs. Not capable of sustaining these costs and having been denied additional governmental provisions, the ELDIS network has been forced to merge with both, Dutch Health Insurance AS, which is the largest health insurer in the country and Dutch General Insurance AS, which is the former's collaborating partner. Starting as a non-profit governmental project to help decrease health-care costs by prolonging it's users' stay and care at home, because of its unprecedented success, the network has been forced to integrate into the private market by selling earlier non-existent shares. The shares of the network are now divided 16% for ELDIS (public), 44% for Dutch Health Insurance AS and 40% for Dutch General Insurance AS, giving the two collaborating insurance companies the highest amount of shares and hence an advantage over decisions for and decision-making processes within the network.

After selling its shares to the insurance companies, the building, expansion and maintenance of the database have in general gone smoothly. There have been though unforeseen legal issues and conflicting interests rising in regards to specific users. Having no prior experience with and on the outcomes a sickness like Alzheimer causes, some clients and their families were ignorant of their rights and responsibilities in such circumstances, as well as unaware of the specifics of their right to privacy as dictated by the country's directives. The first difficulties encountered occurred with the need for granting authorization to disclose particulars of some clients' health files describing their condition as Alzheimer sufferers. Because some of the clients felt fine and in control in moments of lucidity they had not agreed to transfer guardianship to other family members. By the time authorization to process their medical information into the database was needed, their condition had worsened but the final legal resolutions for the transfer of guardianship were not yet confirmed, halting the family's possibility to give authorization and hence the services provided by the network. As stated in the contract signed between the target users and the network, in situations where the administrators find that the vital interests of the clients, for given reasons, do not withstand protection, the services and provisions granted by ELDIS will be halted until further notice. Because the families of Alzheimer sufferers could not give permission for the processing of the necessary data to provide "better services and support", the ELDIS administrators brought the services provided to these clients to a standstill. On the other hand, since ELDIS became part of the insurance companies, conflicts of interest between the three administrative parties have raised. Dutch Health Insurance AS and Dutch General Insurance AS, interested in profits, have raised costs for ELDIS' services. To make matters worst, most of the family members of the ELDIS network users, having their lives and properties insured by these companies, have experienced an increase on their insurance premiums. The insurance companies -owning most of the shares of the network- have assessed the client's database files. With their own interests in mind, they used the information stored in the network's database to calculate potential risks and costs of insuring individuals with a history of dementia in

their family. There after, the companies proceeded to increase health, life and accident insurance premiums for individuals with higher risk.

Discussion for Scenario Two

The scenario depicted above centers on how the relations, actions and decisions of specific key actors involved can give way to dilemmas regarding the sustenance of the right for privacy as dictated in the WbP and of confidentiality of medical records as dictated in the WGBO. These actors -either directly or indirectly related to the network- must also be taken into account when considering the development and use of a tracking and tracing network like ELDIS. Special consideration must given when the technology at hand is enhanced with information and communication capabilities for use within the already vulnerable health care sector. As is underlined in the scenario, the technological features of the network can create social possibilities to the different actors involved at different levels. With correct implementation and use, these features open for social possibilities not only for the target users but also to other actors like care-providers, politicians, insurance companies, etc. On a long-term basis, the network can encompass beneficial outcomes to the Dutch health care system and society in general as well. However, before the technology used in the ELDIS network benefits society, it is subject to the social interpretations and factual use the culture surrounding- and conforming it gives it. These relations and interpretations are themselves driving forces on how the given technology is to be design, developed and work. In other words, the reciprocal social and technological interactions occurring within and for the network act -from early stages- as motivating forces influencing and molding each other at different levels and arenas. The application of this and similar innovations in health care is a straightforward example of the interactions and interrelationships occurring between the social and technological in society. This type of technological development has- and

is driven by the fundamental restructuring the Dutch health care system has gone- and is still going through. In recent years the sector has been aware of developing new trends varying between seeking towards (1) the consolidation of providers and the merging of care-financing and provider organizations; (2) increased use of sophisticated management approaches to share financial risks for care between industry segments, and (3) new participants in the market for analysis of clinical practice¹⁰². On the other hand, the transformations taking place are mostly the result of pressures to reduce rising care costs, enhance the quality of care, the desire to make health care provisions less expensive and transform users of health care services into customers (with all its implications). These trends have raised the establishment of managed care programs (like ELDIS), health maintenance organizations (HMO's) and the entrance into the field of new types of organizations (i.e. insurance companies, pharmaceutical, etc.) with different motives, expectations and interests. The entrance of these actors into the field has lead to a formidable increased use of health data for reasons other than consultation, causing a shift in medical practice from being based on clinical judgements to being based on empirical data. As a result of the reforms ensuing, new technologies have been developed and new actors have entered the field. This development has itself led to the introduction and expansion into the sector of technologies that effectively increase collection, assess and use of patient health data, and to the sharing of these data across different organizations and organizational boundaries. As a result, the different organizations involved in managed care have the opportunity to assess patient health risks, define optimal ways for the management of care, improve the efficacy of specific patient encounters with a health care provider, and further incite the development of clue technologies for the field. These organizations also have the opportunity to use information about the health

¹⁰² National Research Council; 1997, pp. 12-13

care needs of the enrolled individuals with common characteristics (age, gender, and condition) to improve their own and collaborating organizations' care services.

The application to health care of information and communication technologies like ELDIS enhanced with electronic databases providing medical information and the linking of these databases, promote and facilitate intra- as well as extra organizational communication and collaboration. It generates nonetheless growing concerns regarding privacy and more specifically the security of non-disclosure of identifiable health information. As can be expected many organizations welcome this capability for access. But, others fear that enlarging and transporting such information over to different infrastructures may further affect individual privacy. Such concerns expand as more sensitive data such as psychiatric records, genetic information, health cards, etc. of individuals are stored in databases. These concerns are not ungrounded. The main concern around digital representation of health care information parts from the fundamental right individuals have to control the dissemination and use of information about themselves; and, that information about them revealed to some other party not appointed by the individual, may be used to harm their interests.¹⁰³

Before the establishment of databased networks, health information was physically bounded. Its accessibility or copying was delimited to a physical location, making more difficult its movement and spreading. Automation and networking have radically changed the situation. Data is no longer physically bounded. They are easily copied and transferred, and accessible to and from various points. Through accessible databases patients' information can be moved between

¹⁰³ National Research Council; 1997, p. 15

different areas (i.e. administrative, legal, etc.) within one or various networks increasing the risk of intrusions and misuse of the information. Such databases also raise the possibility that more accurate information and more complete pictures of the individuals can be drawn, concentrating lucrative information and making it hence a target for anyone seeking it. In this case, privacy-related conflicts may rise in relation to how the health data of a subject is processed, the reasons behind its collection and procession, and to how the processing itself is accomplished. When inappropriately processed, personal information may end in the wrong hands. The manner and conditions in which the data is managed is extremely relevant for its lawful processing. Therefore and in accordance with the country's data legislation, the subject whose data is being collected must unambiguously have given his/her consent. In the case of a third party having guardianship over the subject, the consent of the legal representative is required. Statistical data such as marital status, profession, etc. of the subject, should not be included in the register, making thus possible to identify -or make- the subject identifiable. A code must be developed for the purposes. In cases where the data subject is identifiable, the personal data should not be kept longer than necessary for achieving the purposes for which they have been collected and processed. In view of the above conditions, an individual's right for privacy could be easier to sustain through technical adaptations and codifying of the information processed on the database. However, the sustainability of an individual's privacy can seem more difficult to withhold in relation to human spheres like outsourcing the building, services and updates of the database or maintaining the processing of data in the context of the activities established for the network. In the case of the former, it is more complex -and even expensive- to audit human actions within the database. The assurance that the intended limits are actually enforced is more difficult to achieve. It is difficult as well to determine what the intentions of the database users are, and if they represent a threat to the patient's privacy (in this case). The concern over privacy here refers to the risk of disclosure

of health information of an identifiable individual to a- or several parties willing to act against the interests of the specific individual, and hence contrasting with established privacy-protection practices of the country. In the case of the latter, because of the expanding roles of existing organizations in the health care industry, keeping the processing of data to the context it was intended for, can become more difficult. As an example and displayed in the scenario are the expanding roles organizations in the health care industry are playing. Insurance companies for instance may establish their own -or merge into- health care providing networks. The entrance into health care of these new types of organizations, and their collaboration with others, further increases the demand for collecting health information. In many cases, agreements are signed to limit the data- sharing among them, but the complex relations developed can make security measures towards privacy sustenance more difficult to guarantee.

With the increased interest in the collection of personal data both in the private and public sectors, technical methods have been created to counteract existing threats. However, the implementation of technical obstacles to counteract these threats is sometimes not enough. Because of time and money pressures, they can in general be incompatible with the efficient and effective operation of the system used by the organizations or providers. On the other hand, the entrance into the sector of “new” organizations can be at odds with the intentions and interests of the sector, as was the case with the insurance companies entering the ELDIS network. The clearest opposing interest here is the reason behind the collection and processing of the patient’s information. Through the collection of the users health information, the network administrators seek on one side to enlarge and improve care provisions for their users, while the insurance companies on the other can use the collected information to ascertain risks and take the necessary measures to fend for their financial interests. These reasons reflect how perceptions over the

collection and use of personal data may vary between individual stakeholders. These perceptions can affect the privacy rights of individuals who are clients of the health system, or more specific for this case, those individuals who receive care provisions from the network. In a situation like the above, the likelihood for misuse of personal information increases largely when different interests are at stake. The network users, having granted permission for the collection and processing of their medical information for the sake of better care provisions, and unaware of other intrinsic relations developed throughout the enlargement and improvement of the network, make themselves vulnerable to the misuse of their medical information. Even though the WbP dictates standards and procedures aiming towards the ethical and legal processing of personal data, it supports to an extent the potential misuse of information –based on the context or reasons behind the need for processing personal data- by organizations, especially those concerning the public sector. Among this sector opposing interests often appear to be higher at stake than in the private. The diversity of opinions and ideals rising within any country’s policy-making processes, as well as the forces, and representations behind them, can make a satisfactory balance regarding citizen’s interests (both collective and individual) difficult to achieve and maintain. As an example, recently developed health care policies in the Netherlands -aimed at lowering costs by allowing the elderly and disabled to live at home as long as possible, as quality and effectiveness are improved- can open for rising conflicts with other types of standardized policies, like the data protection act. This shows that different policies developed in society for different purposes may influence as well the rise of opposing interests by seeking to achieve a balance between individual and collective concerns.

As can be seen, the introduction of the Personal Data Protection Act (WBP) and the Medical Contract Bill (WGBO) in the Netherlands involve consequences for all organizations,

individuals, etc. interested in collecting and processing personal data in both the public and private sectors¹⁰⁴. The use of security measures to prevent unauthorized access to personal data collected in databases is significant for privacy protection. But, such security alone cannot efficiently protect privacy, especially in relation to the spreading use of information and communications technology in the health care sector. Besides assessing patient privacy and data security policies, the expanding growth of ICTs within the sector demands that other issues like the social context in which it is applied, interpretations, and particularly human use/misuse, among other be considered. These in order to ensure that practices and procedures upon application of networks like ELDIS provide satisfying solutions to the appointed goals.

Scenario Three

Technology/System Relations: 24hr Monitoring and Measuring of Medical Parameters Registered and Updated in a Health Card (HC), Downloaded into an Electronic Medical Record (EMR) and Shared with Collaborating Partners.

The scenario above pointed towards how the interactions occurring within technological developments can affect each other, and more specifically, how actors involved at organizational levels and the relations appearing can come in conflict with privacy legislation in the Netherlands. To complete the assessment on the development of ELDIS, the following scenario intends to portrait how decisions made, when solely based on the design and function of the technical artifact can also create difficulties in relation to sustaining the target individuals' right to privacy:

Before entering the ELDIS program, Alice is requested to fill out her medical history form, specify who is bearing the costs of the services provided and the cost-bearer's information. Because her insurance company is bearing the costs for the program and related services rendered by ELDIS, Alice must sign a form authorizing the network to release any information on her and

¹⁰⁴ As stated on: Why privacy matters-Presentation of Privacy Code of Conduct: found at <http://www.registratiekamer.nl>

her condition for payment claims. The release includes both her insurance company as well as other parties working in collaboration with the network.

After signing the contract, a physician working for the network, examines Alice and requests a series of tests and blood samples to be taken. The tests are done at the network's own premises and the blood samples taken are sent to a collaborating laboratory for analysis. This is done as part of ELDIS's strategy to effectively allocate and plan the services according to Alice's needs. In the laboratory, the results of Alice's blood samples are recorded and identified. In accordance with the WGB0's section on medical storage information, the laboratory keeps a register and information on Alice in their records. Through the release Alice signed as part of the contract, the laboratory receives the necessary billing information from ELDIS and directly sends the claim for Alice's blood test and results to the insurance company. All the information gathered on Alice, as well as the results of the analysis are finally scanned into the laboratory's computer and sent by electronic mail to the network's main database. After the information is received, it is then downloaded to the network's electronic medical records (EMR). Alice is issued a health card containing all her updated medical information including medications and doses, personal information and who to contact in case of emergency, among other things. Alice is now ready to receive service provisions specially adapted to her needs.

The test results show that Alice's Cardio-Vascular condition and diabetes have worsened. Considering her condition, the network providers decide that Alice's medical parameters must be constantly monitored. Sensors connected to an alarm designed as a personal organizer (PO) will measure and register her blood pressure, sugar levels and vital signs 24 hours a day. The PO registers the information gathered from the sensors and sends it within seconds to the network's main database. Shortly after, a certified employee collects, enters and, when necessary, updates the received information into Alice's EMR. The EMR translates and updates the data received into Alice's HC. The EMR does not only translate Alice's medical history and medical parameters, but includes her family history, risk factors, findings from physical examinations, test results, therapeutic procedures, medications and her responses to treatment. It also includes the providers' assessment and plans, information of Alice's assent to- and responses to therapy, and her signed release for disclosure of information to other care providers or bill payers. At the end of the day, the updated information is registered once more into the network's main database.

Aware of the limitations caused by Alice's condition, and as another part of their strategy to improve services, ELDIS works in collaboration with various pharmacies. In Alice's case, the appointed pharmacy delivers her medication as needed in accordance with the information received from the network's database. This information is updated as Alice's disease progresses and her medication and dosage change. The pharmacy must therefore with regular intervals, connect by means of a code to the network's main database. This use of each other's database guarantees that Alice receives the required medication and that it is delivered to her at home from either a pharmacy employee or an ELDIS provider. On delivery, all Alice must do is have her HC scanned as confirmation of medication delivery for the pharmacy and as record keeping for the network. The bill is then sent accordingly to her insurance company.

Alice, satisfied by the care provisions supplied by ELDIS, willingly allows continuous access to her personal data. She is unaware of the consequences the constant flow of information could

have for her and her family. ELDIS on the other hand, concerned about its users' well-being, continues providing them the already-established services on top of constantly searching for new forms of collaboration and technologies to further improve their care provisions. The latest addition in improving health care services is the development of an ELDIS web-site. The users can download their own medical files, follow the progress of their disease, and come in contact with care providers and other users by entering their HC number into their personal organizers. Once in, questions can be asked and themes discussed in an open forum. Certified collaborators can download required information on specific users, as well as contact them, and /or any other health care provider as needed. Internet users non-related to the network can search for general information on ELDIS, research plans, publications, etc. on top of to connect to other network-related links.

Discussion for Scenario Three

The scenario created above intends to portrait how technical properties, capabilities and functions of various technologies within the network can rise privacy-related issues. At first sight, the collecting and processing of data seem to occur in accordance with the standards stipulated in the country's privacy legislation: codes are used, ID is needed, only certified personal have access. However, a deeper look into the technologies used and the functions stipulated for the different purposes can prove otherwise as will be discussed below.

Similar to the first scenario, the constant monitoring and measuring of an individual's medical parameters can rise privacy-related issues in regards to other types of privacy¹⁰⁵ rather than informational privacy. Because the other types of privacy are irrelevant for the case at hand, they will not be considered in the discussion. Nonetheless, when tracking and tracing of individuals, and particularly monitoring and measuring of their medical parameters is enhanced with ICT technologies like the Internet, databases, digital health cards (HC) and electronic medical records (EMR) legislation-based data privacy issues become a matter of concern. The widespread use of ICT technology combined with the need of the health care sector to collect patient-identifiable

¹⁰⁵ See discussion on John's scenario

data causes informational privacy issues to increasingly be at stake.

Within the health care system the need to collect, process and store health information has extended to include an increasing demand to share it as well. Health information is shared today not only among health care providers, but also other organizations, such as insurance companies, third-party payers, patient organizations, assessment groups, research institutes, and the growing health services industry (pharmaceuticals, producers of rehabilitation technologies, etc). As stated in the WGBO, in order for patients to obtain optimal health care, providers must receive fulfilling information on the circumstances around the patients health (e.g. family health history, own health background, symptoms). That is, health care providers are dependent on the availability of a complete, identifiable medical record on each patient. Therefore, the entrance into the sector of these new actors increase concerns about system threats to electronically linked health information, misuse and spreading.

As has been pointed out elsewhere, the goals with the development of a technological network like ELDIS, is to improve the quality of health care, decrease costs and restore the users' autonomy and independence their health conditions may limit. Nevertheless, to attain these goals, care providers, health services research institutions and administrative bodies must be allowed to locate and use patient records as well, making optimal health care increasingly dependant on the availability of a complete medical record linked to the identities of the target individuals. To avoid controversy, these stakeholders may assign patient identifiers for use within their own organization and for their own stipulated interests. Controversy could rise though with the prospect of using "universal" identifiers, which could facilitate the linkage of information within

and across larger boundaries like the ones to be found in a network like ELDIS. For example, the prospect of issuing a health card, while making the user more easily identifiable to the different collaborators, will make all medical data associated with that given individual easier to link to other types of data such as financial data, consumer data, family details, etc., many of which are already indexed by government agencies. The issuing of a health data for use in the network can rise issues not only about its potential to link large numbers of personal data transactions but also for discrimination of single individuals, in this case, of already vulnerable individuals.

To decrease these risks the ELDIS administrators may decide to develop their own separate code of conduct or policy with regard to the protection of information. However, even though based on the country's data regulation directives, the policy/code of conduct can for the most part be treated informally by each stakeholder in the network. This attitude itself can cause consensus problems in relation to the need for collaboration and sharing of information within the different stakeholder groups, considering that each stakeholder holds different perceptions towards the use of personal data and the sustenance of an individual's informational privacy. For example, it is likely that Alice's insurance company will agree with other health insurance companies in regards to the boundaries of legitimate access to information within their own business sector, as would a group of physicians. But, their views around legitimate access to personal information are more likely to differ from one another according to the sector they represent. As a result, the movement of data around a network composed of different stakeholders will not necessarily be governed by the policies stipulated by the main stakeholder; fact, that could increase the risk of misuse and of processing of personal information. Data will more likely be treated in accordance with the organizational policies/codes of conduct stipulated by each individual stakeholder and

they might not be consistent with the patient's (in this case user) understanding when signing information release forms.

Another potential issue rising in regards to privacy sustenance as stipulated by the country's directives has to do with the direct violation of security and confidentiality policies by both internal and external agents due to the inadequate processing and storage of data. Internal agents consist of authorized system users who abuse their privileges by accessing information for inappropriate reasons or uses as to view records of friends or co-workers. External threats (also known as hackers) are outsiders who are not authorized to use the information system or to access its data, but who anyhow attempt to access or manipulate data or to render the system inoperable¹⁰⁶. Health care organizations have long foreseen and attempted to counteract intrusion of paper health records by internal threats. But, because until recently only few health organizations were connected to open networks like the Internet, the sector has less experience in protecting health information from technical attacks by outsiders¹⁰⁷. When creating connections to open networks it is essential for health organizations collecting identifiable personal data to foresee and set up necessary countermeasures against stealing and spying of information, or technical sabotage, especially when most of this actions occur without being noticed and when noticed, go officially unreported. Although the WGB0 and the WbP do not explicitly mention conditions for protecting personal data from outsiders, it is an integral part of the tasks and responsibilities stipulated on the acts, that organizations take the necessary measures (systemic and organizational) to avoid the threats of unauthorized access to personal information. The increased connection of (health) information systems to public communications like the Internet,

¹⁰⁶ National Research Council; 1997, p. 29

¹⁰⁷ National Research Council; 1997, p. 29

and the increased flow of health information to electronic networking rise more than ever the risks of exposure of sensitive health data to unauthorized agents and misuse by authorized ones.

Concluding Appraisal on the Scenarios

Scenario 1 depicted an Alzheimer patient that takes to wander at night and experiences moments of confusion, aggression and hallucinations. He represents a danger not only for himself, but for those around him as well. His/her legal guardian must make a decision based on what s/he understands his/her affected family member would have agreed on and is best for them. In the case, due to prior consent the design and functions of the network can help relieve the stress and pressure the progression of AD causes without rising dilemmas around privacy as stipulated in the WGBO or the WbP. Then again, privacy legislation in the Netherlands is limited to informational privacy. It doesn't include spatial, bodily nor accessibility privacy¹⁰⁸, which increasingly become violated as ICTs become more widespread. Intervening third parties like legal guardians and the likes can have consequences for privacy as defined in the WGBO as medical secrecy. Because the WGBO aims to regulate the doctor-patient relation, other parties entering this relation can rise dilemmas around granting access to patient information to other parties. This can also have consequences on the patient's chosen right to keep his/her condition undisclosed to others or, to be kept him/herself uninformed of his/her own condition. It must be stressed here that the progression of a disease like Alzheimer varies from person to person. There are AD sufferers that experience moments of lucidity, where even though conscious of their condition, they feel fine and healthy (specially in stage 1 and the beginning of stage 2)¹⁰⁹ and more often than not, express their outmost desires and wishes. It is in these moments of lucidity

¹⁰⁸ As defined in footnotes 90, 91 & 92

¹⁰⁹ See appendix 3

that their right for privacy is at utmost danger to be violated. They feel capable of exercising their patient-rights and accordingly make their own decisions. But, instead, must submit to decisions made for them by third parties. Yet, as another example of the various relations occurring at different levels and which influence technological development, this situation can soon change, not only in the Netherlands, but also in the EC. People with dementia have been recognized by many influential parties as one of the most vulnerable groups of society and that as such, their rights need to be respected and reinforced specially in respect to fundamental human rights, such as self-determination, freedom and integrity¹¹⁰. Therefore, Alzheimer Europe –as part of an EC funded project- has developed a set of legal recommendations¹¹¹ aimed at improving the legal protection and rights of these individuals¹¹². If implemented, these recommendations may be in conflict with current national laws in some countries forcing policy makers in each country to reform their laws accordingly when the time to change legislation arrives. Transpiring parallel to this scenario, could be the situation described in scenario 2, which centered on privacy dilemmas rising in regards to the relations, actions and decisions of key actors, some of which have just entered the field, promoted by the policy reforms in the country. These actors' actions endorsed by intentions and interests, will cause privacy dilemmas to rise based on the organizational decision made to outsource services and provisions. Unaware of the market potential of the network the administrators did not plan any precautionary measures to support the network's infrastructure in case it became overloaded. The need to support and extend services opened for decisions to expand by integrating new technology and personal to the network. This decision pressed the need for outsourcing areas of service provisions, maintenance and support. Incapable

¹¹⁰ “The legal rights of people with dementia”; lawnet projects: http://www.alzheimereurope.org/lawnet2_short.html

¹¹¹ The recommendations focus on three main areas: guardianship measures, restriction of liberty of movement and Bioethical issues. See also Appendix 6

¹¹² “The legal rights of people with dementia”; lawnet projects: http://www.alzheimereurope.org/lawnet2_short.html

of sustaining outsourcing costs, the administrators were forced to introduce the network to the stock market, where parts of it was bought by actors whose main interests came in conflict with the network's. Specific privacy issues rising here have to do with the intra- and extra organizational communication and collaboration networking and outsourcing promotes. Further enhanced and supported by automated databases they promote indiscriminate easy access to vital information on individuals. In the scenario's case, two insurance companies bought ELDIS share. This at first sight mere financially strategic move cost the users not only their right for privacy but an increase on their own and their next of kin's insurance fees. Similar to scenario two is the last and third scenario. Although it centered mainly on privacy issues rising in base of decisions made solely on the technical properties (design, capability and function) of the network, some dilemmas rising were closely related and similar to those discussed in scenario 2. Privacy issues do not rise in face of specific technical properties because technology is neither autonomous nor independent from its social surrounding and structure. It cannot work alone. First when the social and the technical meet and interact does the potential for mistaken use and misuse appears and hence privacy dilemmas rise.

The introduction of databases into health care further increases the danger for violating single individuals' right to privacy. On one side they facilitate and assist the health care field upon collection, processing and storing of patient-identifiable data for research treatment and follow-up purposes. On the other, it becomes more and more vulnerable to access from unauthorized, as well as authorized parties in search of information. In this particular, an individual's right for privacy becomes at stake in face of the more collective one known as right for access to information. Common to all three scenarios and promoted by the increased use of information and communication technology (ICT) –but not discussed here– is the violation of physical privacy

through surveillance. ICT enhanced with cameras allows surveillance of individuals at home and work. The combination of these features and capabilities in a network like ELDIS will allow not only direct monitoring of the target users' by authorized parties but will also allow interested parties to create a portfolio of these individuals and their family's routines, consumer habits, and the likes. Even though the Netherlands has not yet targeted policy reforms to include this type of privacy on privacy protection acts, it has been addressed in ethical studies on ICTs, and by experts on the field, which can mean that further reforms are on the way.

The scenarios portrayed in this chapter depict potential situations the network can experience. The purpose behind their creation has been to assess potential privacy sustenance dilemmas rising in base of relations and constituents directly appearing within the ELDIS network, in addition to less direct ones but which could also affect the targeted individuals' privacy. Chapter four presents conclusions drawn in basis of the findings in this thesis and accordingly, recommendations for the Institute for Rehabilitation Research (IRV) in the Netherlands.

Part Four

General Findings, Conclusion & Recommendations for the Institute for Rehabilitation Research (IRV)

General Findings

The findings listed below underline society's need to stop relying in two-tracked approaches separating promotional activities from control and regulation ones. These findings are (in no specific order):

- Information and communication technology is being focused on to a greater extent for improving the quality and decreasing the costs of health care. This focus on use of ICT's in health care increases the risk of misuse and spreading of sensitive, identifiable health information.
- In general social, technological and political changes are accelerating the intensity of information and communication technologies in society and hence the move towards a so-called information society. This development is rapidly forcing changes on established citizen rights and the appearance of new rights and responsibilities on governments, organizations and individuals.
- Organizations collecting sensible information must approach improving health information security in a more aggressive and conscious manner. Even though Internet connections and databases present dangers for privacy sustenance from outsiders, insider abuse (conscious or not) is the primary problem in sustaining privacy.
- In individual organizations health information is vulnerable to authorized personnel misusing their privileges and outsiders (so called "hackers") breaking into the system. Organizations have been centering on developing mechanisms for protecting information (both paper and automated) from abuse by authorized users, but protection from intruders must be strengthened.
- With the spread of networking and outsourcing health organizations –alike other types- are becoming more vulnerable to access from intruders. Besides privacy vulnerability, access to important health information system can also have consequences for services granted. (For example an outsider crashes the system and denies access to care providers dependant on the systems for allocating home-care services). Respectively,
- Patients play key roles in addressing privacy security. Their concerns and expectations can help set clearer standards for sustaining privacy, especially where collaboration between various health care and patient organizations is taking place.
- Most patients and consumers of health care services are unaware or unconcerned about the uses their health information is put through, nor the organizations possessing it. Respectively,
- Patients must become more conscientious of their rights and responsibilities, not only as consumers of health care but, as members of a society promoting increased use of information and communication technology. Accordingly, they should have more control over the ways

information about their health is collected, used and disseminated among specific stakeholders, especially where tight collaboration takes place.

- Laws and regulations should be developed for individuals with special needs and limitations (like individuals suffering from dementia). If patients have really become the focus of reforms occurring in the Dutch health care system -as stated by specialists in the field-, special consideration should be given to these individuals' capabilities. Their standing point differs widely from that of healthy individuals in society.
- The existing regulatory policies for protecting personal and patient identifiable information (WbP and WGBO) are insufficient and long-winded in face of the increased data sharing and health care services with ever-larger boundaries. Respectively,
- Policy makers must re-access the already established statutes. The WGBO and WbP center their statutes to legislation of human processes in the collection of data but neglect assessing the technological process used for it. In this sense, the acts should be extended and complemented to include technology.
- The interactions and inter-disciplinarity of the relations occurring in the Dutch health care system increase the need for collaboration and communication not only between different organizations in various levels but government, research institutes, technological developers, the market forces and consumers as well.
- Health organizations mostly focus allocation of resources in expanding the functionality of health care information systems, undermining allocation of resources for protecting systems already in place.
- The biggest concern regarding privacy sustainability is related to the widespread sharing of patient identifiable information throughout the health care industry. But, medical records (paper/automated), biometrics, national ID cards and linkages between databases both public and private, etc. also threaten it.
- The vulnerability of other types of privacy, such as physical, etc. should be considered as well, especially in regulations promulgated to sustain patients' autonomy and integrity. The sustainability of these basic human rights is not only dependent on the sustainability of informational privacy.
- The actual health care structure in the Netherlands, and even the WbP give care-providers, payers (insurance companies), healthcare institutions, administrative bodies and pension funds¹¹³ –among other- incentives to collect patient identifiable health information (the same data it is supposed to protect).
- The increased emphasis on controlling costs, quality and improving services, further increases the value of such information. Data collected for a good stated purpose can also be used for different, unstated ones.
- Adequate protection of personal data depends on technological, organizational and social practices and collaboration.
- The expectations and future of information and communications technology in the health care industry depend to an extent on the way privacy issues are handled and solved. Subject to this are also businesses specializing in electronic commerce and related services in health care.
- IRV's contribution does not end in the product-development phase of the technology to compose ELDIS. The development of this network will securely open for further research in

¹¹³ as stated in the WbP Article 21, Sections 1 to 5

related areas, making ELDIS an experimental test-bed for other type of basic or applied research. And,

- As part of the technological development process, the IRV will have helped shape the network to what it will be and hence form an integrated part of it.

Conclusion

The aim of this study has been to assess privacy dilemmas rising with a specific design and function of ELDIS in basis of the capabilities and needs of the Dutch elderly and disabled. This, in order to submit recommendations to the IRV on potential technological adaptations to avoid these dilemmas from rising. As the scenarios demonstrated, information and communication technology has the potential to offer a wide specter of benefits to Dutch health care. Electronic Medical Records (EMR) for example offer health providers more effective ways to assess health data for supplying health care services. Meanwhile, data networks enable sharing of information over geographic boundaries between patients, providers and other health care-related organizations in order to help conduct analyses on relevant statistical data for the field –among other things. However, to achieve these benefits, concerns around privacy sustenance and security of health care information must be lessened. As the recommendations and findings below describe, health care providers have to adopt a series of organizational, technical and social practices and measures to successfully protect health care- and personal information in general, as stipulated in the WGBO and the WbP.

The recommendations stated for the IRV are built in reference to the findings and course of actions that took me there. Among the course of actions that gave form to this thesis was the manner in which the commissioner of this thesis treated the development of such a network. Although it may seem at first irrelevant for the case, a deeper look assures the relevance of this treatment for the future of the ELDIS network. Common to most technological developers the

aims elaborated by the IRV seemed to be anchored on views of technological development as a linear model in which technological development occurs as a one-way flow of information, ideas and solutions emerging from basic science into R&D, production and finally marketing & consumption¹¹⁴. They seem to conceive technology as a fixed or ‘black-box’ solution in invention stages, that once established, is introduced and spread through the market to impact society in any possible way, treating the process of invention-innovation and diffusion as separate stages occurring in the linear process¹¹⁵. Seemingly, with this mindset, the institute believes that adaptations done to the technological device in research and product-development phases will “guarantee” the network’s legal and ethical use, and ultimately, its “success”. However, this manner of looking upon the relations and interactions occurring between society, science and technology resembles technological deterministic views addressing that technology impacts work, economy, and society as a whole. In other words, implying that technological change produces social and organizational change. These views on the processes and interactions occurring within technological development will hinder the development of the ELDIS network by presenting unrealistic, one-sided, half pictures of the realities encountered and involved in such networks. In this regard, the scenarios and arguments developed in this thesis sought to validate technological development/change, for the IRV, as the social process that it is, stress the importance of implementation stages as an integrate part of ELDIS’s development process, and accordingly, present a fulfilling assessment of the aims established. So it has been that an STS social-analysis of the form, content and context of this technological network has helped me highlight and problematize the technological development process of ELDIS in face of privacy sustenance. As a result, areas of the aims stipulated at the beginning of this thesis have been

¹¹⁴ Based on Tidd, J. et.al.1997; Williams, R. & Edge, D.; 1996

¹¹⁵ Based on Pinch, T & Bijker, W.; 1984 and Edge, D 1988

reassessed in order to open ELDIS's black box. First, to analyze privacy dilemmas rising with a specific design and functions of the technology alone in base of the users grants half pictures of the realities the network will confront. Second, developments in the ICT field point to the unlikeness of standardized information and communication technology making it necessary for technological developers to assess each design and functions in relation to its context. And third, albeit all the research and progress done on ICT, an ideal tracking and tracing network developed specially for health care is still far from being a practical reality.

If regardless of all, the developers of ELDIS insist in talking about an 'ideal' or "successful" privacy-sustaining tracking and tracing network, it must be stressed that such a network must function efficiently in terms of space, time and costs, and be capable to cope with the dissimilar constituents integrating it¹¹⁶. The influence of the social sphere around such a network -including diverse actor interpretation, capabilities and interests among other-, are essential for developing a thriving network as is expected by the development of ELDIS. Moreover, decisions made for/in given situations and which may seem unrelated to the network, might influence the outcome and hence possibilities for the creation of this type of network as well. As an example, the health care policy reforms presented in chapter 2 can be mentioned. Incited by social pressures to increase effectiveness, services and costs of health care services and especially home-care, policy/decision- makers have open for ICT technologies -like tracking, tracing, automated measuring of medical parameters, etc.- to be considered for application in an already informational privacy-vulnerable field. This means that infrastructures seemingly disconnected to technological development processes, play decisive roles as well. Another factor playing an important role before further developing ELDIS or any technology for use in health care, but,

which is often taken for granted in early research and development stages, is the natural progression of diseases and health conditions. There are phases in the progression of diseases like Alzheimer, Parkinson, Multiple Sclerosis, etc. that are not controllable by the social, the scientific, or the technical but greatly influence the application and use of new technologies for health care. In this regard, the user's mental and physical state, play decisive roles, especially on implementation stages. In the situation of a demented elderly for example, it cannot be expected for these individuals' to understand, interpret and correctly use the technology conforming the network on basis of a technology developed for the healthy part of the population. In this specific case the limitations of these individuals already present themselves a threat to the vulnerability use submits their personal data to. It is thus correct to say that the development of ELDIS is not just a mere problem-solving process for the actual and future Dutch health care situation. It also involves other processes -like general economic and political- in building alliances to support interests (e.g. supplier firms, technologists, potential users, funding bodies and regulators with the necessary resources and expertise) and a thriving environment for the technology and the social in the network.

Various authors have described these relations as 'socio-technical systems'¹¹⁷, 'socio-technical' ensembles¹¹⁸, or actor-network¹¹⁹. Common to all though is that the technological development process (called innovation by some) is mostly characterized by the interactivity of its actors and stages on top of insufficient knowledge, contradiction and uncertainty. It is thus clear that 'success' in developing a technology is not just a matter of having the necessary funds or achieving good technical solutions. In ELDIS's situation, because of inherent differing

¹¹⁶ Based on Rip, A; Misa, T.J. & Schot, J., 1995; Peeters 2001

¹¹⁷ Hughes, T.; 1983 as cited in Williams, R. & Edge, D.; 1996

¹¹⁸ Bijker, W.; 1993/1995 as cited in Williams, R. & Edge, D.; 1996

¹¹⁹ Law, J. & Callon, M.; 1992 as cited in Williams, R. & Edge, D.; 1996

perspectives and knowledge bases, the network could experience difficulties in securing effective flow of information between database experts and health care specialist groups needed to protect an individual's privacy, making it necessary to enroll other actors, including users, and even competing suppliers. In addition, experience has showed that when transferring technical systems to different contexts than built, they need to be reconfigured, translated, and redesigned to meet the requirements of the new contexts, validating the assertion that the shaping process of a technological development begins in early R&D stages. This discards the idea of treating the technical as a fixed entity that can simply be transferred without any or simple modifications enabling application in different contexts¹²⁰. Conversely it reinforces that technology is a social product, patterned by the conditions of its creation and use, and that the close and reciprocal interactions occurring among technological development stages transform technologies between their initial conception and eventual application.

In basis of the above it can be concluded that the development of a tracking and tracing network enhanced with ICT for use in health care increases even more the possibilities to collect, store, process and distribute personal data. With the increase of these possibilities the potential for violations of individual privacy also increases. There is no doubt that there is information that is private and at risk but there is also other, that remains unclear. Accordingly, it is not easy to coordinate a system of data protection that meets the needs of data subjects, supplies health care reforms, sustains privacy and functions in practice. In any case, for the ELDIS network to efficiently protect its users' informational privacy, a combination of technical, organizational and social practices and measures are required. This combination of practices and measures are

¹²⁰ Williams, R. & Edge, D.; 1996

central for developing appropriate countermeasures for protecting privacy from systemic, technical and organizational threats in health care. However, one shall not forget that different organizations have different intentions, face different threats and differ in the resources they can use to support security. Therefore, the selection of the combination of practices and measurements should be subject to organizational decisions according to the network's individual circumstances.

Recommendations for the Institute for Rehabilitation Research (IRV)¹²¹

- The network could open for programs or courses offering its consumers a better insight of their rights and responsibilities as patients and part of the network.
- The network could adopt a set of technical and organizational policies, practices, and procedures to protect patient-identifiable health care information collected by them. Some examples are¹²²:

Technical Practices and Procedures

Individual authentication of users: Every individual in the network should have a unique identifier (or log-on ID) for use in logging onto the organizations information systems. Where appropriate, computer workstations should be programmed to automatically log off if left inactive for a specified period of time.

Access control: Procedures should be in place for ensuring that users can access and retrieve only that information that they have a legitimate need to know.

Identification badges: Employees, medical staff members, and any other individual related to the network and with authorization to retrieve health information should be required to present their organizational identification badges both when entering any network related premises or whenever the request health information.

Warnings on health records: Putting pertinent disclosure rules on health record (paper /automated) can continuously remind staff members of their confidentiality obligation and policy requirements.

Requisition System: A requisition (can be paper or automated) document request could be implemented to access a health record. Simultaneously,

¹²¹ This section is based on: For the record: protecting..., 1997; Czeowski, 1984; Blume, 1998; Hustinx, 1999; Moore 1998; Raab, C. & Borking, J. 2001

¹²² For the record: protecting..., 1997; Czeowski, 1984; Raab, C. & Borking, J. 2001; Moore 1998

Charge-out system: A charge-out or sign-out system could help identify what records have been removed/retrieved from files.

Audit trails: The network should keep -in retrievable and usable form- audit trails (review logs) that log all accesses to clinical information. The logs should include the date and time of access, the information or record accessed, and the user ID under which access occurred.

Physical security and disaster recovery: The network should limit unauthorized physical access to computer systems, displays, networks, and medical records. It should provide basic system functions and ensure access to medical records in case of any eventual emergency. It should store backup data in safe places or in encrypted form.

Protection of remote access points: If/When using Internet connections the network should install Privacy Enhancing Technologies (PETs) or other technologies for privacy protection which provide strong, centralized security and allows outside access to only those systems critical to outside users. For multiple access points the organization should consider other forms of protection to protect host machines that allow external connections. It should also require a secure authentication process for remote and mobile users such as those using home computers. Organizations that do not implement either of these approaches should allow remote access only over protected lines.

Protection of external electronic communications: The network should encrypt all patient-identifiable information before transmitting it over public networks, such as the Internet. If it cannot encrypt the information it should either refrain from transmitting it electronically extra-organizational or it should do so only over secure lines. Internal policies should be developed to discourage including patient identifiable information in unencrypted e-mails.

Software discipline: The network should exercise and enforce discipline over user software. It should as a minimum, install virus-checking programs on all servers and limit the users ability to download or install their own software. These technical practices should be supplemented with organizational procedures and educational programs to further provide protection against software with increased misuse potential and to raise users awareness of the problem.

System assessment: The network should formally assess the security and vulnerabilities of its information systems periodically.

Organizational/Social Practices

Security and confidentiality policies: The network should develop explicit and clear security and confidentiality policies that express their dedication to protect their users health information. The policies should specify the types of information considered confidential, the people authorised to release the information, the procedures to be followed when making a release, and the types of people who are authorised to receive the information.

Security and confidentiality committees: The network should establish formal points of responsibility to develop and revise policies and procedures for protecting patient privacy and for

ensuring the security of information systems.

Information security officers: The network should name an information security officer who is authorised to implement and monitor compliance with organisational security policies and practices, as well as with the WGBO and WbP. The officer should maintain contact with the Dutch Data Protection Authority's (Registratiekamer) appointed commissioner.

Education and training programs: The network should create programs to ensure that all the users of their information systems/database receive at least a minimum level of training in relevant security practices and knowledge regarding existing confidentiality policies before being granted access to any information systems. It should also create an educational program for the patients (or next of kin/legal guardians) to receive instruction on their rights and responsibilities in the network and especially in regards to privacy.

Sanctions: The network should develop a specific and clear set of sanctions for violations of confidentiality and security policies to be applied uniformly and consistently to all violators, regardless of job title. It should adopt a zero-tolerance policy to ensure that no violation goes unpunished.

Improved authorisation forms: The network should develop an authorisation form that will improve patients understanding of health data flows and limit the time period for which authorisations are valid. The forms should list the different types of organisations to which identifiable or unidentifiable information is commonly released.

Patients' access to audit logs: Health care providers working for the network should give their patients periodical inspections of all accesses to their electronic medical records and to review such logs without waiting for the patients request.

- Because no countermeasure will make the network 100% resistant to misuse, it should on a constant basis continue updating and assessing their capabilities (technical and human) once a measure or mechanism for protecting data has been established.
- The network should promote increased government and health care industry involvement in order to create the infrastructure necessary to support the privacy and security of health information in general, especially electronic health information.
- The network should promote involvement of the Ministry of Welfare, Health and Cultural Affairs in collaboration with the Dutch Data Protection Authority to establish a health information security standards committee to develop and update privacy and security standards for all users of health information with need for membership. Membership should be drawn from existing patient organizations representing the consumers.
- Increased working collaboration between the state and industry should be promoted in order to promote and encourage an informed public debate to determine an appropriate balance between the privacy concerns of patients and the information needs of various users of health

information.

- The network should promote working collaboration between the Ministry of Welfare, Health and Cultural Affairs, the state, local governments, health care researchers, and the health care industry in general to establish programs to promote consumer awareness of health privacy issues and the value of this information for their care, administration, and research.
- The network should expand collaboration with professionals, organizations and industry groups to expand leadership roles in educating members about privacy and security issues. This can be done by means of conference discussions, seminars and publications –among others.
- The network should collaborate with state and local governments in developing, providing and taking specific steps to improve information security technologies for health care applications.
- To facilitate the exchange of technical knowledge on information security and the transfer of information security technology, the network should establish formal liaisons with relevant government and industry working groups.
- The network should promote collaboration between the Ministry of Welfare, Health and Cultural Affairs with the Dutch Data Protection Authority to support research in areas that are particularly important to protect data in the health care industry, but that might otherwise be left unpursued
- The network should explore different approaches to access control that are inexpensive and easy to incorporate into existing operations and that allow access during emergency circumstances.

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Appendix 1

1A General Dutch Legislation Concerning Personal Data¹²³

1983	Dutch Constitution, Article 10
Content	Article included during constitutional revision. (1). Right to protection of the private sphere, (2/3). Obligation to lay down 'privacy with regard to personal data' in law.
1988	Wpr; Dutch Privacy Act (Wet personenregistraties)
Aim/Content	Act works out Article 10 of the Dutch Constitution (1983) and the Treaty of Strasbourg (1981) out. A general privacy act which contains principles similar to the Data Protection Principles. Applies to registrations of personal data, that is to collections of personal data about various individuals, which are either automated or organised in order to be consulted in a systematic way. Inclusion of conventional medical records depends on particular case.
1993	Bgg; Sensitive Data Decree (Besluit gevoelige gegevens)
Aim/content	Administrative measure (AMvB) on the basis of art. 7 Wpr (1988). Defines certain personal data, including data referring to a person's health, as sensitive. Introduces additional, stricter rules with regard to these data.
2000	Wbp; Personal Data Protection Act (Wet bescherming persoonsgegevens)
Aim/content	Act is implementation of the EU Directive (1995). As such it includes the Data Protection Principles. General privacy act, replaces the Wpr(1988) and the Bgg (1993). Applies to all processing of data, from initial gathering to final (possible) elimination. Act has a wider scope than the Wpr and clearly includes conventional medical records.

1B Specific Dutch Legislation Concerning Personal Data in Health Care¹²⁴

1995	Wgbo; Medical Contract Bill in the Dutch Civil Code (Wet op de geneeskundige behandelingsovereenkomst)
Aim/Content	Establishment of the specific individual basic rights, the patient rights, in order to empower individual patients. Wgbo aims to offer the legal framework for a good co-operation between doctor and patient, which should in the first place be based on mutual trust. Regulating co-operation in the form of a contract emphasizes that the doctor-patient relationship should be as equal and even as possible. Concerned with personal data generated in the context of this contractual relationship. The Wgbo is a part of the Dutch Civil Code, which means that the general rules of the Civil Code are applicable. Bill establishes minimum patient rights and has an imperative legal force, which means that exceptions can not be made which put the patient at a disadvantage. Other regulations can contain more patient rights or regulate them in more detail.

¹²³ Appendix 1A is based on Van Eck & van de Pol & Zandee, 1999; Leenen & Gevers, 2000 and Nouwt, 1997

¹²⁴ Appendix 1B is based on Leenen & Gevers, 2000 and Nouwt, 1997

Appendix 2¹²⁵

Patient Rights Concerning Informational Privacy.

Proposed by the Health Council of the Netherlands in 1978.¹²⁶

Patient right	Content
Notification and refusal	<p>When the recording of data in a certain registration is not really obvious, the individual should be informed about which personal health data are about to be recorded and for which purpose. Exceptions: notification damages patient; to be decided by the Dutch Data Protection Authority.</p> <p>The individual has the right to refuse this recording. This right is limited since certain services, like medical care and health insurance, require a minimum of information. Exceptions: legal exceptions, e.g. in case of contagious disease.</p>
Access	<p>A patient has the right to be informed in an understandable manner about diagnosis and treatment.</p> <p>Exceptions: information too shocking for patient, diagnosis insecure; to be decided by doctor.</p> <p>In addition to this, a patient has a right of access with regard to personal health data that concern him or her. No right of direct access, possibly damaging for patient. Access via (independent) trusted third party, person who functions in profession binded by professional secrecy and code of ethics.</p> <p>Exceptions: subjective data containing hypotheses, written requests when patient could be pressured by a third party</p>
Rectification	<p>Following the right of access, a patient has the right to rectify (remove, change or complete) false or irrelevant personal data. Limited right since a doctor can not be forced to change a professional opinion.</p>
Elimination or anonymity	<p>A patient has the right to request for personal data to be eliminated or made anonymous. Patient has to be informed about consequences before request can be complied with. This right is limited by conditions that take the interests of doctors and third parties into account.</p> <p>Exceptions: legal exceptions with regard to certain data</p>
Consent	<p>Following professional medical secrecy, an individual has to consent in writing for his or her personal data to be accessible for a third party. This consent is not a carte blanche for all future uses of these data. Patient, or (independent) trusted third party appointed by patient, has to be informed about pros and cons of potential accessibility. Even if the supply of data to a third party outside an institution is in the interest of the patient's treatment, a form of consent that is less strict is required. Those who finance a patient's treatment are entitled to receive the minimum of information required.</p> <p>Exceptions: emergency situation (implied consent); financiers of treatment entitled to receive required minimum of information; control medical care and some legal cases.</p>

¹²⁵ Borrowed from Peeters; 2001

¹²⁶ Published in *Advies inzake registratie van medische en psychologische gegevens en de bescherming van de persoonlijke levenssfeer (privacy)*

Appendix 3

Facts on Alzheimer's Disease in the Netherlands and in General:

- Age is known to be the most common cause for degenerative dementia like AD, which is a progressive, irreversible, degenerative brain disorder with no known cure. The symptoms of the disease include memory loss, confusion, loss of language skills, personality changes, impaired judgment and disorientation.
- Every year in the Netherlands, approximately 21,000 persons become victims of Alzheimer's disease. Figures from 1999 estimate that more than 130.000 individuals are suffering from AD in the country and that over the next thirty years, as the population age continues to rise, the number is expected to have increased to 300.000¹²⁷. Alzheimer's disease affects approximately 5 percent of the elderly population aged 65 and older.
- Individuals in their 40s and 50s¹²⁸ can also develop the disease, but the incidence increases with advanced age. Studies indicate that approximately 20 percent of those over the age of 80 are suffering from Alzheimer's disease and that the disease is one of the leading causes of death among the elderly.¹²⁹ In the Netherlands, there are currently over 300 nursing homes, and Alzheimer's patients occupy almost half of the beds in them.
- Approximately 50 percent of all Alzheimer's patients are cared for in the home, often by their spouse or near relative¹³⁰.
- Alzheimer's disease usually runs through two to fifteen years with an average duration of seven years. Functioning continues to deteriorate over this period until patients require care and monitoring 24 hours a day. The disease effects on and progression affects each individual differently. The process of the disease's development is clinically broken in general into three stages, which causes a decrease of the patient's mental and physical condition. These stages are¹³¹:
 - Stage oneVictims gradually show signs of losing their mental faculties. They exhibit minor memory loss, lack of energy, less spontaneity, mood swings and slower reaction and learning time. Alzheimer patients may lose track of what they are saying in mid-thought and begin to display a lack of feeling for others. They prefer the familiar and tend to avoid new situations.
- Stage two

¹²⁷ According to statistics presented at The European Alzheimer's Research Symposium of September 17 1999 organized by IARF. See also <http://www.alzheimer.nl/EARS.htm>

¹²⁸ Within 15 years, as much as 35 percent of the population of the Netherlands will be older than 50. Source: IARF See also <http://www.alzheimer.nl/EARS.htm>

¹²⁹ Even though a definite diagnosis of the disease cannot be made until after death, when an autopsy is performed on the brain.

¹³⁰ Source: IARF See also <http://www.alzheimer.nl/EARS.htm>

¹³¹ As described on summary of the The European Alzheimer's Research Symposium of September 17 1999 organized by IARF. See also <http://www.alzheimer.nl/EARS.htm>

Patients are obviously disabled here. They are less familiar with reality. Short-term memory is very poor while the distant past may remain clear. They forget time and place, speech becomes difficult, and family and friends are not always recognized. In this stage, patients can no longer function alone.

- Stage three

Patients are completely dependent on others for their care. Aside from the mental deterioration, patients' physical condition may begin to degenerate. Patients are disorientated and can no longer find their own way around. They develop sleeping problems and may start wandering at night. Patients become incontinent and have problems with walking, sitting and eating. They eventually lose ability to chew and swallow, and there is greater vulnerability to infections and other diseases. This stage eventually leads to death by complication such as pneumonia rather than the dementia itself.

The main characteristics of Alzheimer's disease can in short be summed up as¹³²:

(1) Memory loss: can affect daily life by leading to communication problems, safety hazards and behavioural problems.

(2) Communication problems due to the development of the Syndromes of Apraxia, Aphasia and Agnosia

- Apraxia: inability to carry out voluntary movements (tying shoelaces, etc.) despite having muscular power, sensibility and coordination intact.

- Aphasia: difficulty or loss of ability to speak or understand spoken, written or even sign language due to damage on the nervous system. Aphasia can be accompanied by echolalia, which is the involuntary repetition of words or phrases in general or spoken by another person.

- Agnosia: loss of the ability to recognize what objects are and what they are used for. With regard to people, they may fail to recognize who people are.

(3) Personality change: Individuals suffering from AD might behave differently than accustomed. They have periods filled with aggression, frustration, depression, etc. Experiencing frequent mood changes is common, especially in the first stage of the disease.

(4) Behaviour: A common symptom of the disease is wandering, both during the day and at night. Other symptoms are incontinence, aggression and disorientation in time and space.

(5) Physical changes: AD sufferers may experience weight loss even when normal food intake is maintained. It can also occur because the individual forgets to chew or how to swallow, which is typical in the third stage of the disease. Another consequence of the disease is the wasting away of muscles bed-ridding the sufferer as a result. As the disease progresses into its final stage, vulnerability to infections increases causing many sufferers death by pneumonia.

¹³² Dutch Alzheimer Association. See <http://www.alzheimer-ned.nl/1024.htm>

Appendix 4

Interview Guide 1: Care Providers/Patient Organizations

Demographic Data:

Education/experience:

Type of organization the care-provider works for:

Years working with this organization?

Position in the organization?

Job performed (details)

Years working with patients suffering from this type of dementia (AD)?

Part I: Experience with patients suffering with Alzheimer:

- 1) According to your experience working with sufferers of Alzheimer, do you feel the needs of the patients are fulfilled within the different stages? Explain.
- 2) How do you experience the workload with patients with dementia?
- 3) Could this load be lessened somehow? Give details.
- 4) What do you consider as limiting factors in your work with AD patients? Regulations/Other
- 5) What would you change in the type of work you perform?

Part II: Questions around the ELDIS technology and privacy:

(Present ELDIS, how it is expected to work and objectives.)

- 6) Are you familiar or worked with any type of social alarm network? How as your experience been?
- 7) Do you feel this type of technology could alleviate your work pressure/load? Explain.
- 8) According to your experiences, are there any limiting factors you can think of with the implementation and use of this type of technology?
- 9) Can you think of any conflicting issues (regulation, etc.) that could appear in your line of work with the use of this technology? Explain.
- 10) Do you believe a protocol (code of behavior, practice) for dealing with privacy issues for this type of technology should be developed before implementation in institutions, etc.? What should it include?
- 11) (Explain my research, then...) What kind of privacy issues, in your experience, do you think could appear with the implementation and use of this type of technology?
- 12) Besides data confidentiality, do you consider that the use of this technology would be an invasion of other types of privacy towards the patient? Explain.
- 13) In your opinion and according to your experience, what could be done to develop a TTT, which is ethically and legally acceptable?
- 14) What is your general impression/opinion on the implementation and use of this type of technology?
- 15) Should Health-Care employees work hand in hand with policy-makers & technological developers (or programs) in projects like this one? Explain. How is it really in practice?

Notes/Comments

Ps: leave doors open for complementing questions...

Appendix 5

Interview Guide 2: Care-Recipients

Demographic data: (family members of AD patients)

Sex of patient: Male Female

Age the AD prognosis was made:

Domicile (home, institution, etc.):

General development of disease:

Part I: Patients needs:

Explain: Even though AD affects each individual differently, the disease process is generally broken down into three stages.

1st Stage: In this stage, victims gradually show signs of losing their mental faculties. They exhibit minor memory loss, lack of energy, less spontaneity, mood swings and slower reaction and learning time. They may lose track of what they are saying in mid-thought and begin to display a lack of feelings for others. They prefer the familiar and tend to avoid new situations.

1) Based on the above, what are the basic needs in this stage? In which areas did you experience the most need for support/help?

2nd Stage: Patients are obviously disabled at this stage. They are less familiar with reality. Short-term memory is very poor while the distant past may remain clear. They forget time and place, speech becomes difficult, and family and friends are not always recognized. In this stage, patients can no longer function alone.

2) Based on the above, what needs were present in the 2nd stage? In which areas did you experience the most need for support/help?

3rd Stage: Patient is completely dependent on others for their care. Physical condition may begin to deteriorate as well. Patients are disoriented and can no longer find their own way around. They develop sleeping problems and may start wandering at night. They also become incontinent and have problems with walking, sitting and eating. They eventually lose ability to chew and swallow, and are more vulnerable to infections and other diseases. This stage eventually leads to death.

3) What were the specific needs at this stage? In which areas did you experience the most need for support/help?

4) Do you feel the needs (at the different stages) were taken into consideration and fulfilled by your primary health care center or center in charge? How/Why?

5) Do you feel this situation could be improved? How/why?

6) Did you feel you could say or do something to improve the situation? Explain

Part II: Questions around privacy based on the ELDIS technology:

Explain the ELDIS tracking and tracing system, how it is expected to work and the objectives with it.

NB!! This section is hypothetical in the sense that the interviewee has already gone through the experience of having a family member sick with the disease. The sick patient has died at the time of this interview.

7) Do you have any experience using such a social alarm? (did you have the possibilities for using such a system at the time your family member was diagnosed with AD?) Would you have been interested in using such a system? Why?

8) Based on your loved one basic needs during the disease, do you consider this technology to be capable of alleviating the needs of both the patients and their care providers? (is it realistic)

9) Give examples of what the technology will do. Ask: What else would you like it to do?

10) Do you feel this system would in any way (have) invade(d) your family member's privacy? How?

11) Would you have agreed to reveal to other (3rd) parties in the network (like police, ambulance driver, nurse or any other care-provider in charge of answering the distress call) your mother/father's condition, possible symptoms of the condition and, eventual medication and doses of medication they would need at any given time? Explain.

12) Besides confidentiality of medical files, is there any other type of invasion of privacy that you feel would be violated with the use of this technology? Explain.

13) Do you feel the above mentioned is an invasion of your right for privacy and confidentiality of medical file? Would you have been willing to sacrifice this right for the sake of the possible benefits brought up by the tracking and tracing system? Explain.

Notes/Comments

PS: leave doors open for complimentary questions

Appendix 6¹³³

Guiding Principles Drafting Alzheimer Europe's Recommendations to EC Commissioners on the Rights of People with Dementia

These principles are recommended to promote autonomy, adopt least restrictive care environments with minimum intervention in the affairs of the adult for the minimum time necessary, and maintain support and acknowledge friendships and family ties the person has developed as a means of understanding his/her well-being and personhood.

Governments are urged to take the necessary steps to ensure that an early and accurate diagnosis is obtained.

Every person diagnosed with dementia should have the right to be informed of the diagnosis.

People with dementia should be informed about the advantages of writing an advance directive and appointing a guardian/lawful representative (preferable, but not necessarily altogether). The necessary structures or facilities should be put into place by governments to ensure that this is possible.

The adult with incapacity should be involved as much as possible in the procedure to establish the guardianship measure and for the duration of it, including choosing the guardian/lawful representative and deciding on his/her duties.

Informed consent (in writing where appropriate) must be obtained before investigation/treatment can be given and it should not be presumed that the person with dementia cannot give such consent purely on the grounds that s/he has incapacity. However, if due to the nature and extent of his/her incapacity, s/he cannot make a decision and there is no advance directive or provisions for a personally appointed guardian, a guardian/lawful representative should be appointed with responsibility for treatment and care decisions.

That the whole issue of research involving adults with incapacity due to dementia be investigated and discussed.

Non-voluntary placement for the purpose of medical treatment should involve a formal and legal/administrative process to determine the appropriateness, location and kind of placement required. In the case of non-voluntary placement solely for care, a guardian/lawful representative should be appointed with responsibility for deciding on the place where care should be provided.

A personal advocate should be appointed to guide and advise him/her in all matters relating to placement both during and after the process to establish it, and also whenever a measure intended to further restrict his/her liberty of movement is applied. The personal advocate should not be linked to the establishment in any way. S/he should be responsible for informing the person of his/her rights, helping with complaints or appeals and regularly checking on his/her personal welfare.

Multidisciplinary teams (e.g. doctors, psychologists, jurists, carers, social workers and other specialists) should be created to discuss the issues raised and contribute their views and expertise in order to produce an improved version of these guidelines.

Governments should ensure that family members and/or close persons responsible for the care of the dying person are granted sufficient time off work to care for and accompany him/her.

¹³³ Based on "The legal rights of people with dementia"; Lawnet projects:
http://www.alzheimer-europe.org/lawnet2_short.html